



The independent review of
**Learning Disability
and Autism**
in the Mental Health Act

How we did the review

A report on the review's processes

January 2020



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1 What this report is about

This report is about what we did in this review.

This was a review of a law. In this review we had to work to understand people's experiences of the law. We also had to work to understand how Scotland's mental health law could meet the human rights duties which Scotland had at that time.

In a review such as this the process is very important. The people affected by a law must be fully involved in reviewing that law. We wanted this review to be fully accessible for the people affected by the law. This included people with learning disability, autistic people, carers, and people with limited or different communication.

To do this we spent a lot of time developing the processes for the review. We think that we were successful overall in making a very complicated and technical review of law accessible for people with a range of communication styles. This took a lot of time, consideration and effort from the review team. At times we made choices and did things that were very different from what people expected.

This report tells you about what we did. The processes that we developed have received recognition and praise from people with lived experience and organisations including the Scottish Human Rights Commission and Enable Scotland. We must learn from experience and in this report, we describe the things that went well and the things that could be improved upon.

We hope this report is useful for other people who may wish to carry out reviews in the future.

In 2001, the Millan Committee reported on how Scotland's mental health law should change. The report said that learning disability and autism should be covered as 'mental disorders'

1 What this report is about

by Scotland's Mental Health Act¹, but that this should be reviewed.

When it was written, people said that Scotland's Mental Health Act was one of the best mental health laws in the world for human rights. After that time, the United Nations realised that governments were not doing enough for the human rights of people with disabilities. This is why the United Nations made the Convention on the Rights of Persons with Disabilities (UNCRPD).

At the time of this review, it seemed that there was no mental health law in the world that met all of the human rights standards in that Convention. The Scottish Government has to try to make all Scots (Scottish) laws fit with that convention, and with other human rights. This can be difficult.

This review was commissioned to make recommendations for mental health law that would enable the Scottish Government to meet its human rights obligations for people with learning disability and autistic people.

Our final report with recommendations is [here](#).

The easy read version of the final report is [here](#).

Please note that our website will be archived, and will be taken down in 2020. Web addresses will change. You will be able to find out how to get to our archived website [here](#).

¹ The full name of Scotland's Mental Health Act is the Mental Health (Care and Treatment) (Scotland) Act 2003

2 Our approach to this review

Human rights

People who took part in a scoping study ([link](#)) thought that the review should take a human rights-based approach. The review's executive decided to do this.

Near the start of the review, the review's executive asked the Scottish Human Rights Commission for advice on how to do this. We also spent time in the first months of the review thinking and talking about how to take a human rights-based approach. You can read about our human rights-based approach [here](#).

Our human rights-based approach and human rights framework helped us with the review's governance and with our processes of engagement. They also gave us a basis for our evidence gathering and reporting.

Here are some examples of how taking a human rights-based approach affected our processes:

Human rights and engagement

We think that involving people with lived experience made it possible for us to get good results in this review. But it is not just good practice to involve people with lived experience. Scotland has committed in international law to fully involve people with disabilities in reviews of laws that affect their lives and rights, and in other processes that are about this convention.

Scotland has agreed to the United Nations Convention on the Rights of Persons with Disabilities, as part of the United Kingdom. When Scotland is developing laws and policies and putting these into practice, we have to 'closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations' ([link](#),

2 Our approach to this review

article 4.3). These are organisations that are run **by** people with disabilities, not **for** people with disabilities.

We worked with organisations of persons with learning disability, with autistic people's organisations, and with a range of groups of people with lived experience. We had to work to make sure that the review's governance and its consultations were accessible to all people with learning disability and autistic people who might want to take part ([link](#), section 45). To do this, we involved autistic people, people with learning disability and unpaid carers in the planning of the review.

The human rights-based approach told us that people who faced the biggest barriers to realising their rights should be prioritised. This meant, for example, that throughout the review we spent more time meeting with people with lived experience than meeting with professionals.

Human rights and the remit

The Scottish Government asked some organisations to do a scoping study for the review ([link](#)), and then made a remit for the review. The remit is the list of things that we had to think about and report on in the review.

The remit required us to get evidence from a wide range of sources, engage widely with people who had a personal or professional interest, and reflect this evidence in our final analysis and recommendations.

We focussed on –

The operation of the Mental Health Act – are people with autism and learning disability well served?

The role of psychology in the Mental Health Act

The definition of mental disorder under the Mental Health Act in relation to learning disabilities and autism

2 Our approach to this review

The criminal justice system and the interaction with the Mental Health Act

The use of psychotropic medication (current prescribing practices)

To respond to the part of our remit that asked whether people are “well served” by the act, we chose to find out how well the current Mental Health Act promoted and protected the human rights of these groups of people.

A focus on the law

A human rights-based approach should be based on the rights that are set out in Scots law, UK law and international laws. We mainly looked at how Scotland can comply with the Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights.

This focus on human rights was helpful at times when we were challenged about whether change was needed. The human rights duties placed on the Scottish Government made it clear that there is a need for change in the law.

Human rights framework

With the help of legal experts, we created a human rights framework for the review ([link](#)). This was essential. We took a framework from the World Health Organisation as the basis for this framework and added human rights and themes that we thought were most relevant to this review.

Human rights and gathering and analysing evidence

The human rights approach lead us to give more time to people with lived experience than we might have done in a traditional consultation. We think that professionals and people with lived experience had equal opportunities to take part in this review. For that to happen, we had to make more effort and put more

2 Our approach to this review

time into meeting and hearing from with people with lived experience.

We used the human rights framework to bring together evidence and to give equal weight to evidence from all people. The framework meant that we could connect everything people told us to human rights, no matter how complicated and no matter how people told us. For example, in stage 1 we used the human rights framework to develop a concrete 'easy read survey' and a Talking Mat² that asked about people's experiences.

This made it possible for us to analyse all responses together. For example, we could analyse responses from people directly experiencing care in a hospital setting under the Mental Health Act, alongside responses from national professional organisations such as the Royal College of Psychiatrists.

In the last stage of the review, we decided not to structure our consultation documents by human rights themes. We learnt in the first stage that many people, including professionals, were unfamiliar with human rights. For this reason, we chose a different way to express our suggestions for the law. We did include a description of human rights that are relevant to each of our suggestions.

²Talking Mats is a system with sets of symbols and a very simple method that supports people with limited communication skills to talk about complex topics ([link](#))

3 The stages of the review

Starting out

At the start of the review, the Scottish Government thought that the review might take 18 months. When we worked out what time it would take to fully involve people with lived experience in the review, we found that it would take 2 years.

This was because we had to make each stage both accessible and correct in law. Also, we had to give everyone enough time to understand and respond to everything that we wrote. This included time for advisors and time for people who took part in the review.

Stage 1

Stage 1 was about experiences of the Mental Health Act. We worked to find out how the Mental Health Act affects the human rights of autistic people and people with learning disability.

Stage 2

In stage 2, we asked organisations how the law could promote and protect human rights better in future. We spoke to experts in the law and experts in services for autistic people and people with learning disability. We spoke to experts from the UK, Ireland and four other nations. We held some collaborative group meetings with people with lived experience, professionals, and legal experts. Then we developed ideas on how the law could be in future.

Stage 3

In stage 3 we asked people for their feedback about our ideas for the future of mental health law.

Final report

Based on all of this, the review team wrote a final report with recommendations for the Scottish Government.

4 Who helped us to run the review

The Executive

The executive (the main team) of Andy, Catherine and Simon met whenever they needed to, to make any decisions that needed to be made.



Andy Rome was the independent chair of the review.



Simon Webster was the secretary to the review.



Catherine Evans was the project manager for the review.

The review was independent. This means that no other group of people or other organisation could tell the review's executive what to do. The review had to be hosted (supported) somewhere. The Mental Welfare Commission for Scotland hosted this review but did not make any decisions for the review.

The 'review team' was the executive, plus three people who worked to support the review for part of 2019: Fiona Hamilton, Lynn McBean and Emily Cheesman. Fiona gave admin and IT support. Lynn and Emily worked on engagement and data.

4 Who helped us to run the review

Advisory groups



We set up the review's advisory groups near the start of the review.

We did not choose people to represent any organisation. We chose people to give the review's executive the expertise that we needed to make the review work well. We chose advisors for their expertise and their ability to work well with other people.

Advisors

We needed to find the right advisors for this review. We took the time to select the right people. These were people with lived experience, professional experience or both.

For people with lived experience, we sent out invitations to apply to be an advisor, through organisations of persons with disabilities, autistic people's organisations and third sector organisations.

We met with people who were interested in being an advisor at a place that suited them. We had an informal interview with them. Then we invited some people to be advisors.

Our advisors with lived experience became volunteers of the Mental Welfare Commission for Scotland. This helped us to make clear our responsibilities to advisors and to be clear about the commitment that the advisors made to the review. We had a policy on how to work with volunteers. We were available to help advisors work through any difficulties that affected them in their role. Also, the Mental Welfare Commission helped the review team to make sure that we followed the law on things like data protection for the advisors.

4 Who helped us to run the review

To find professional advisors, we did not go to professional organisations. We met with individuals who are experts in their field and selected the mix of expertise that we needed for each group. We invited professional advisors who we thought would work well with other people including people with lived experience.

We held training for advisors on human rights and on mental health law. The training was given by two of our advisors who are experts in this.

What the advisory groups did

Advisors knew from the start what their role was. The advisory group members advised the executive on how to run the review so that the review got the evidence it needed.

Some of the advice was about how to make the review accessible. Some advice helped us to make sure that the review team spoke to all the people we needed to, to find out everything the executive needed to know.

The review's executive did not ask these advisors for advice on what to say in the review's reports or recommendations.

The advisory groups met six times during the review.

There were also 'ad hoc' advisors. The review's executive asked those advisors for advice on the same sort of topics when they needed extra advice, from time to time.

The advisors are listed in section 11.

5 What our advisors did

How the advisory groups worked

Following the human rights-based approach, we decided that advisory groups would need to be small so that people with lived experience could take part in full.

There were 4 advisory groups. These are shown below:



Advisory groups had three advisors with lived experience and three advisors with professional experience. People with lived experience were able to bring someone with them to meetings to support them to take part.



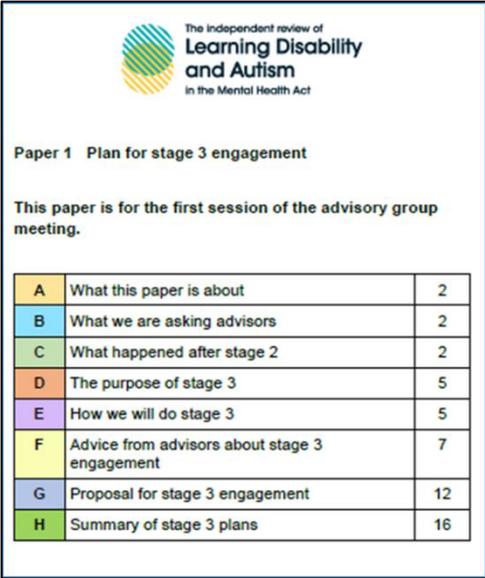
5 What our advisors did

Advisory group meetings

There were three stages in the review.

Before each stage, each advisory group met separately over two weeks. At those meetings, the advisors gave advice on the review team's plans, before the review team made decisions about the next stage.

During each stage of the review, the advisory groups had one meeting together. At those meetings, the review team gave the advisors an update on how the stage was going and asked for advice on any problems with that stage. The review team also told the advisors about their initial thoughts for the next stage of the review and asked the advisors for suggestions.



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Paper 1 Plan for stage 3 engagement

This paper is for the first session of the advisory group meeting.

A	What this paper is about	2
B	What we are asking advisors	2
C	What happened after stage 2	2
D	The purpose of stage 3	5
E	How we will do stage 3	5
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We gave papers to our advisors two weeks before each advisory group meeting.

There is an example of an advisory group paper in section 10.1.

We always made sure that we got these papers out two weeks before the meeting because this mattered to people. People could use them to prepare for the meetings, instead of getting papers at the last minute. They could ask questions about the papers before the meeting, take notes on papers, and take them the meeting.

There was one set of papers for each meeting. We wrote all of the information for the advisory groups in plain English.

5 What our advisors did

We offered to meet with our advisors with lived experience during the two weeks before each advisory group meeting. This gave advisors the chance to talk through the papers and to ask any questions they wanted to ask.

After each meeting, we gave all the advisors two weeks to make any more suggestions that they wanted to make.

We didn't write minutes from advisory groups. We wrote notes of people's suggestions and we put these on our website.

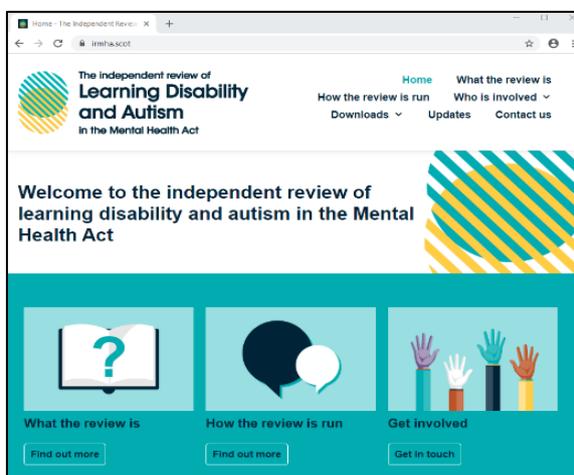
We didn't put people's names against the suggestions in the notes. We hoped that this would help to give equal weight to suggestions from advisors with lived experience and advisors with professional experience.

Accessibility

Before we started to 'take evidence', we did lots of work to try and make the review accessible in every way we could. This was an important part of the review's human rights-based approach. In this approach, people who face the biggest barriers to realising their rights should be prioritised.

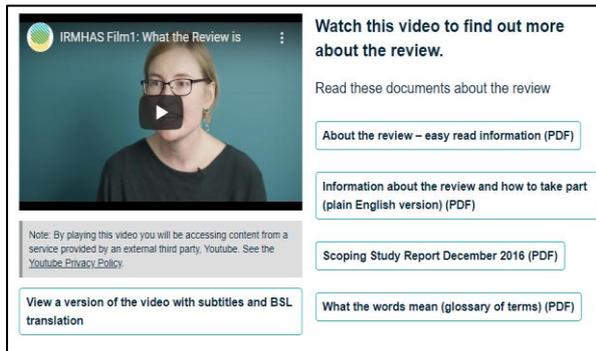
We tried to make all of our information accessible to everyone.

This included:



Our website ([link](#))

6 How people took part in the review

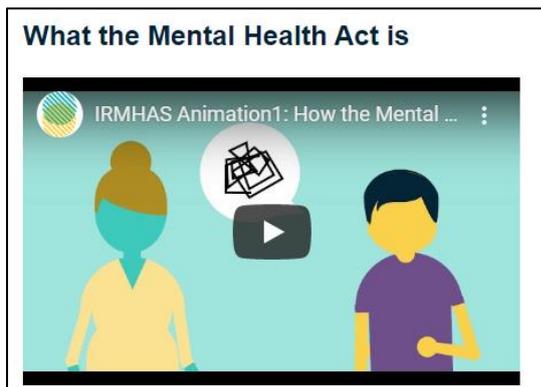


Videos about each stage of the review, including British Sign Language.

A link to an example is below.

Film 1: What the review is ([link](#)).

With subtitles and British Sign Language ([link](#))

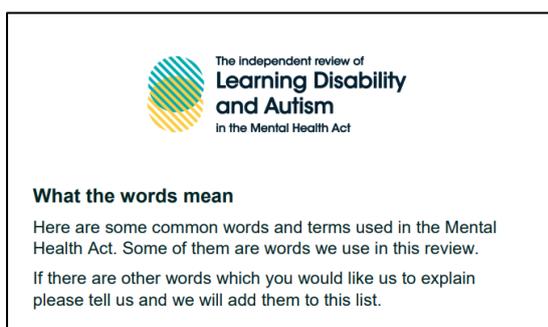


An animation about what the Mental Health Act is

A link to an example is below.

Animation: How the Mental Health Act can work ([link](#)).

With subtitles and British Sign Language ([link](#)).



A glossary to explain what words mean

6 How people took part in the review

Meeting people

The executive's first meetings were with organisations of persons with disabilities and autistic people's organisations. Our first public meeting was with people with lived experience and professionals.

Before stage 1, we agreed on which groups of people would have the biggest barriers to taking part. Our advisors helped us develop ways of engaging with people to try to overcome these barriers. Prioritising these groups of people meant that we did not have time to meet with professional organisations at this stage.

Stage 1

In stage 1, we found out about people's experience of the Mental Health Act. We asked people with lived experience about the same things that we asked professionals.



Our evidence from people with lived experience came from meetings, from phone calls, and from surveys that people did online, or completed and sent to us. We also used Talking Mats.

For people who do not communicate through speech, we met with unpaid carers to help us understand the experiences of those people. Unpaid carers told us about their own experiences, separately.

We prioritised going to meet people in hospital, including people in high-security hospital wards who might not have been able to take part unless we visited them.

Professionals gave evidence through surveys.

6 How people took part in the review

Surveys

The surveys we created in stage 1 (and in stage 3) allowed people to choose which sections they completed. People did not have to complete every section. People could choose how to respond in each stage of the review and could choose which of our topics and questions to talk about.

Reports

We also chose 'main reports' that told us what outcomes might be needed for mental health law. The main reports were things that other people and organisations had already written. These reports had been written by people with lived experience or by professionals. We used our stage 1 evidence to create a list of outcomes (see page 62) and a set of examples that guided what we talked about in stage 2 (see page 104).

Stage 2

In stage 2 we went out to meet organisations of people with lived experience. We asked professional organisations to come to meet with us.

In stage 2, groups gave us suggestions about how the law could better promote and protect human rights in future. We met with groups of people with lived experience wherever they needed to meet. Professional groups came to meet us.

We also met experts from this country and other countries, in person, by phone or by videoconference. We invited experts by experience from other countries to speak with us, but all chose not to.

We held some collaborative groups to discuss some suggestions. These groups included people with lived experience and professionals.

6 How people took part in the review

Stage 3

In stage 3, people told us what they thought about our suggestions for change. We met with groups of people with lived experience wherever they needed to meet. Some professional groups came to meet us, and we went to some meetings of professional groups

In stage 3, we also met some people who were in hospital and some school students. We adapted our materials for the people that we met. Where possible we worked with staff who knew the people we were talking to, to try to make sure our materials were suitable for the people we were meeting with.

Anyone or any organisation could respond to us with a written response or through our online survey. Both plain English and easy read surveys were available online.

Other things we did to make the review accessible

Our advisors helped us to improve our ideas for making the review accessible, for all of the review.

For stage 1 and stage 3, we also checked what impact our plans could have on different groups of people. This is called an impact assessment. We had a meeting with people who were not in the review team to think this through.

Here are some of the extra actions we took after the impact assessment and after advice from our advisors.



We used a flyer to advertise the review.

6 How people took part in the review



Some groups use Discord, which is software that gamers use to communicate. It can be used so that people can take part in a meeting without being there in person. We used Discord in a meeting.



We used social media to tell people about the review.

These are some more of the things we did so that people from all over Scotland could take part:

We offered to pay for additional support that people might need to take part, for example, from independent advocacy.

We bought prepaid envelopes. We gave these out to people to send their survey forms back to us.

We paid people for their travel costs.

We found out about interpretation and translation services and we offered these services to people.

We contacted organisations about the review that are for different groups of people to tell them about the review. For example groups for people from different ethnic backgrounds and for people with sensory impairment.

6 How people took part in the review

We visited services and groups in some rural areas.

We offered to take notes or make sound recordings of meetings. Several groups took up this offer. After making sound recordings, the review team typed up what people had said in those meetings and sent that to those people. Those groups could use these notes to make their submission to the review.

We visited meeting venues to make sure that they should be good for autistic people and people with learning disability. We also created venue guides so people knew what to expect.

We offered to meet carers at times that would work for them. We organised meetings especially for carers and invited carer organisations to attend.

We used one type of online survey system in stage 1.

We found that we needed a more accessible system, so we invested in a different online survey system in stage 3. You can see this [here](#).

6 How people took part in the review

Organisations of persons with disabilities

The United Nations says that the effective and meaningful participation of persons with disabilities, through their representative organisations, is at the heart of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The Committee for this convention gives guidance in its general comment 7 [here](#). The easy read version is [here](#).

This guidance is on organisations of persons with disabilities ³. It says that representative organisations are led, directed and governed by persons with disabilities. A clear majority of their members should be persons with disabilities themselves. These organisations are different from organisations **for** persons with disabilities, which provide services and/or advocate on behalf of persons with disabilities.

This review has ‘a duty to inform organisations of persons with disabilities of the outcomes of [the review’s] processes, including an explicit explanation in an understandable format of the findings, considerations and reasoning of decisions on how their views were considered and why.’

There are different types of organisations of persons with disabilities.

We worked with:

An **umbrella organisation**, Inclusion Scotland. This is a coalition of representative organisations of persons with disabilities.

3. The United Nations previously called these ‘disabled persons organisations’.

6 How people took part in the review

Self-advocacy organisations. People with learning disability had these organisations:

People First Scotland

Advocating Together

People First Highland

Autistic people had these autistic people's organisations.

Autistic Mutual Aid Society of Edinburgh

Autism Rights Group Highland

Edinburgh and Lothian Aspergers Society

Triple As, Aberdeen

Scottish Women's Autism Network, which is also an **organisation of women and girls.**

Autistic people's organisations are not defined separately in the CRPD. This is a name chosen by autistic people. However, the Convention on the Rights of Persons with Disabilities does apply to autistic persons. We looked for **organisations and initiatives of children and young persons with disabilities**, but we could not find any to take part in the review.

We also worked with groups of people who were supported by organisations **for** persons with disabilities, such as ENABLE's ACE groups and several other groups.

Groups that represent unpaid carers were also important in this review, such as the National Carer Organisations of Scotland and Autism Rights. The United Nations recognises that **'organisations including family members and/or relatives of persons with disabilities ... are pivotal in facilitating, promoting and securing the interests and supporting the autonomy and active participation of their relatives....'** The United Nations' criteria for organisations of persons with

6 How people took part in the review

disabilities seem to only include carers organisations as 'organisations of persons with disabilities' if groups of persons with disabilities want to be supported by the unpaid carers, and if the role of unpaid carers is to assist and empower persons with disabilities to have a voice and take full control of their own lives (section 12(d) of general comment 7).

Our response to organisations of persons with disabilities is at the end of this report, in section 13.

7 What we did with what people told us

Evidence

It was important to treat people with lived experience and professionals equally when analysing and reporting on our 'evidence'.

In this review, evidence was anything that told us about how the law promoted and protected the human rights of autistic people or people with learning disability. Evidence is also anything that told us how the law could be better at promoting and protecting human rights in future.

Stage 1

We used data analysis software to bring together everything that people told us in the stage 1 survey. We then used spreadsheets to make sense of all the information, bringing together what people told us under each human rights theme, and in relation to the review's remit.

Stage 2

We noted all the suggestions that organisations made at our meetings. We then brought the suggestions all together into a spreadsheet and considered all of the suggestions in relation to each human rights theme.

For experts, we found reports from the experts that were relevant to the review and read those. The meetings with experts helped the review's executive to get a better understanding in each area.

Stage 3

We brought all of the responses to the stage 3 consultation together in a spreadsheet. We considered all of the responses for each of the proposals that we had made. When these responses raised questions about the proposals and the law, we asked legal experts for perspectives and considered those.

7 What we did with what people told us

Reporting

Stage 1

To report on stage 1 evidence, we used our human rights themes to bring all the evidence together. We did not separate the evidence into lived experience or professional evidence in our report. This helped us to give equal weight to all the evidence.

The evidence from stage 1 told us that even when good care is provided, the Mental Health Act sometimes fails to protect the human rights of autistic people and people with learning disability.

This meant that we needed to create suggestions on how the law should be in future. We took what we had found in stage 1, and used that information to create a list of outcomes ([link](#)) for mental health law for autistic people and people with learning disability. We also created some 'examples' of situations that people might experience under the Mental Health Act. Those examples were made up but reflected the sort of experiences that people had told us about in stage 1.

Stage 2

We used the list of outcomes and the examples to guide our discussions with organisations in stage 2. In stage 2, organisations and experts gave us hundreds of suggestions on how the law should be in future, to promote and protect people's human rights. We worked through all of these suggestions and used them to develop ideas on how the law should be in future. We tested our initial ideas with several small groups of people with lived experience and professionals. These groups were called collaborative groups.

7 What we did with what people told us

Stage 3

Next, we created some more detailed suggestions on how the law should be in future. Those suggestions went into the plain English consultation document for stage 3.

Instead of just 'translating' this document into easy read, we took the ideas from the plain English consultation document and made them into stories. The stories were used to give concrete examples of how the ideas might make a difference to people if the changes were to happen. We included a story to show what could happen now and another version of the story to show what could happen in the future so that people could see what the difference could be.

Discussion at our advisory groups told us that this approach could help to explain our complicated ideas to people, and it could also help people to understand that we were not talking about changes that would happen in their own lives straight away.

Final report

It would not have been possible to show how all of the evidence in the review influenced the executive's thinking, leading to the final report. We decided to focus the final report on how we think the law should be in future. This approach still led to a long final report, but we think that the style of the report is as easy to read as it could be.

Some groups found the long easy read document useful in stage 3. Not all groups did. We decided that the best way to communicate our final recommendations in easy read was in a shorter, more traditional report.

8 Views about the review's processes

This section gives a range of views about the review's processes from people who were involved in the review.

To write this section we have drawn from our knowledge of feedback we have heard throughout the review. This feedback was mostly given informally, by people who took part and by professionals. We did not have an evaluation of our approach with everyone who participated.

At our last advisory group meeting, we asked advisors to tell us what they thought of the process and their experience as advisors. This feedback is summarised below.

We have also given a response to some of this feedback which we think will be useful for future reviews.

General views about the approach

Advisors said that overall they thought the review made genuine attempts to engage with people with lived experience. This was not “tacked on”.

They also said that the review had stuck to its timescales.

This was a challenge for a large review and the review team agrees that this was an important area of success.

Human rights-based approach

People we met and spoke to were generally and instinctively in favour of taking a human rights-based approach. However many people were not familiar with what a human rights-based approach was. The review team spent time learning about this approach and explaining it to advisors.

One advisor told us that they did not understand the approach until halfway through the review, which made it harder for them to give advice.

Another advisor said that the review team had done a good job of explaining human rights.

8 Views about the review's processes

The review's human rights based approach was been acknowledged as an example of best practice by the Scottish Human Rights Commission.

The review team feel that the human rights-based approach helped the review because:

It helped us to define our remit more clearly.

It helped us to focus on participation and to prioritise people who faced the most barriers to participation.

It provided a framework for us to use for the whole review.

The framework meant we could look at evidence from different people and compare it.

It helped us to explain why there is a case for change.

Stage 1 engagement materials

Feedback about our stage 1 materials was positive.

Many people said they liked the easy read survey, including professionals.

We had feedback from people in hospital wards that the visits to wards had gone well and that they felt people were able to take part well.

People have said that it was good that we used Talking Mats. The review team are sure that there were people who took part in stage 1 who would not have been able to take part if we did not have the Talking Mat. Some of those people gave limited responses, but they were able to take part. We were able to use all of this information in the review because we worked to design the Talking Mat to fit with the human rights framework.

Stage 1 report

We received feedback that our stage 1 report in plain English was well written and easy to understand. One person said it was refreshing to see a document like this written in this way.

8 Views about the review's processes

One person in hospital wrote to the review to say thank you for the report.

The review team think that the stage 1 report was an important document for the review. It summarised all the evidence we had collected in stage 1 and set the direction for the next stage.

Stage 2

We had feedback that the examples we developed for stage 2 were very helpful, especially for people with lived experience. Two advisors who were present at stage 2 meetings said that both meetings went very well and that people were able to engage well because of the examples. Two organisations were able to take the examples and use them with people they knew to gather feedback without input from the review team.

Stage 3

Some feedback we had from the stage 3 survey referred to our methods. This feedback was been both positive and negative.

Some groups we met said that the easy read materials were good and helped people to engage.

Other groups and individuals said that the material was too long and complicated. Some people also said there was not enough time to complete the surveys. Some people said that group members did not understand the concepts in the easy read survey. However the proportion of people who responded to say "I do not understand" was very low.

Other people said that the easy read material did not have enough detail in it.

Some advisors also said the easy read material could have been improved. They said we could have asked advisors to be involved in creating the easy read material. An advisor also suggested that we should have involved a speech and

8 Views about the review's processes

language therapist in developing the easy read material, to make it more accessible.

The review team were able to adapt the easy read material for use with different groups, including people who were in hospital. This was done by working with staff who knew the group or the individuals. It meant that people were able to take part who would otherwise not be able to take part.

The easy read material was created just before the launch of stage 3. There was not enough time to ask advisors to help to create it or to seek help from outside the review team.

For a future review to improve there would need to be more time allowed for creating easy read material. More time would also be needed to give people time to respond.

Some clinicians thought that the easy read material for stage 3 was biased or could lead to bias because it only showed a positive outcome for each proposed change.

In contrast, some legal experts thought that there was no difference, in essence, between the approach that we used in the easy read document and the approach that was used in the plain English survey. As would be expected in any consultation, the review's stage 3 consultation materials all proposed solutions to address current issues. This is what the easy read document did.

We chose to use a storytelling approach to stage 3. This was based on advice from advisors, who also told us that we would need to include a "before" and an "after" scenario, to show what difference we hoped that the change would make.

We were also advised that we should not try to relate the idea to the person's own experience. This is because, if we did, some people might think that the change was going to happen for them in real life, straight away.

8 Views about the review's processes

For these reasons, we chose to use the story approach and to include a before and after scenario which showed the difference a change in the law **could** make. When we met with people to use stage 3 materials this was explained to people.

We checked the responses that we had to stage 3 to see if there was bias in responses to the easy read document. In the final consultation, we invited all respondents to give full comments, and also to give their level of agreement or disagreement with each of our proposals. We used three survey formats – easy read, plain English, and the plain English 'summary survey'. Across all formats for response to the final consultation, there was strong support for most of our proposals.

All three survey formats gave the same general pattern of responses. Across all survey formats, more than half of responses said 'I like the idea' and very few responses indicated 'I don't like the idea' or 'I don't understand the idea'. Different sets of respondents tended to use different survey formats. From the information available, it is not possible to say that the materials led to biased responses from participants.

It is clear to us that this approach enabled many people to engage with very complex topics about the law who would otherwise have been excluded from this stage of the review. We did not base our final decisions about what to recommend on the number of people who liked or did not like an idea. We considered the responses carefully, including all comments.

8 Views about the review's processes

Advisory groups

All lived experience advisors and the vast majority of professional advisors were very positive about their experience. A very small number of professional advisors were not happy about their experience.

The things that advisors thought were good about their experience were:

There was a balance of people with lived experience and professionals

The information came out when it was supposed to, and people had time to read it

The information was written in plain English

Volunteer advisors could meet with the review's project manager before meetings.

The review team were approachable.

There was a variety of people involved as advisors

Advisors enjoyed the meetings

Advisors appreciated the opportunity to take part as an advisor

People said they enjoyed being part of the review process

Advisors enjoyed hearing about others' experiences

An advisor thought that the standard of contributions from all of the advisors was high, that there was a range of deeply insightful, constructive comments from advisors, and that the review could not have been conducted any better.

Some advisors said they think other reviews should learn from this process.

8 Views about the review's processes

The things people thought were not good, or could be improved included:

Being part of an organisation but taking part as an individual, which meant not being able to talk about the review with others in their organisation.

Having anxiety about coming or not being able to contribute.

Having to go to different venues. A consistent venue would have helped.

Some advisors said that more meetings or more chance to keep in touch with the review would have been helpful.

The review's executive agrees that this could have been helpful. If advisory groups were to meet more often in future reviews the review team would need to be expanded.

A small number of advisors felt that their skills were not being used properly by the review team.

One advisor felt that their advisory group did not have the focus that it should have had. They felt that the timing of the meetings in the review's process meant they were not able to contribute effectively.

On the other hand, one advisor said they were unhappy with their role because they were not able to contribute to the review's recommendations as an advisor and were only able to comment on the process. They suggested that other reviews should allow advisors the chance to contribute to the recommendations.

To allow this, the review would have had to have taken an entirely different approach. For example, the review would have had to ensure that all relevant organisations had the opportunity to be represented as advisors to the review.

8 Views about the review's processes

The review's advisory groups would have needed to be much larger. The review's executive thinks this would have made the process less accessible and independent.

The executive feels that having a process where advisors were still able to give their feedback on recommendations during the consultation, along with everyone else, was the fairest and most accessible way to run the review.

Three words to describe your experience...

We asked advisors to give us three words to describe their experience. Here are all the words people gave us:

validating, informative, encouraging, objective, constructive, reflective, confusing, frustrating, curious, disconnected, valued, open, engaging, meaningful, inclusive, fun, interesting, valuable, experimental, learned a lot, innovative, accessible, listened to, involved, included, accepted, frustrating, disappointing, disregarded, enjoyable, included

8 Views about the review's processes

The executive's views on the process

The review's executive would strongly recommend taking a human rights-based approach to future reviews of law. The reasons for this are that:

The approach allows the development of a strong legal basis for the review

The approach enables the review team to focus its resource on engaging with people who face the biggest barriers to participation

To successfully implement a human rights-based approach:

Time is the most important resource, to allow people to participate effectively. This review took 2 years. Additional time would have allowed even more effective engagement processes to be implemented.

Human resource is needed. This review team was small and future reviews may need to consider increasing the staff team required to carry out national reviews of law.

Awareness of human rights needs to improve generally, amongst the public but also services and staff.

9 Materials: human rights and outcomes

We used these materials to guide processes in the review.

9.1 The review's human rights based approach

Purpose: To guide the executive in running the review

The Review is taking a human rights-based approach.

We are using the approach that is set out by the Scottish Human Rights Commission.

If you want to know more about this approach, you can read below or read this document:

http://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

This approach has principles called the **PANEL Principles**. These are:

Participation

People should be involved in decisions that affect their rights.

Accountability

There should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.

Non-Discrimination and Equality

All forms of discrimination must be prohibited, prevented and eliminated.

People who face the biggest barriers to realising their rights should be prioritised.

Empowerment

Everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.

Legality

Approaches should be grounded in the legal rights that are set out in domestic and international laws.

9.1 The review's human rights based approach

This approach also uses the **FAIR process**.

We need to think in this way:

Facts

What is the experience of the individual?

Is the individual being heard and if not, do they require support to do so?

What are the important facts to understand?

Analysis of right(s) at stake (See the reference at the end for explanation – 1)

What are the human rights or issues at stake?

Is the right to life or the right not to be subjected to inhuman or degrading treatment at stake? If so, these rights are absolute and cannot be restricted.

Can the right be restricted? What is the justification for restricting the right?

Is the restriction on the right 'proportionate'? This means - is it the minimum necessary restriction to meet the aim or is a "sledgehammer being used to crack a nut"?

Identification of shared responsibilities

What changes are necessary?

Who has responsibilities for helping to make the necessary changes?

Review actions

Have the actions taken been recorded and reviewed and has the individual affected been involved?

(1) If you want to know more about what it means to restrict human rights, you could look at:

Can human rights ever be restricted? EHRC

<https://www.equalityhumanrights.com/en/what-are-human-rights/how-are-your-rights-protected>

9.1 The review's human rights based approach

How we will apply a human rights-based approach to the Review

The PANEL principles are given above.

These principles can be applied to all decisions that the Review makes, including decisions about processes, recruitment decisions, decisions on engaging with stakeholder groups, and decisions on recommendations.

Participation	Getting evidence	Involve people with lived experience of all levels of ability
	Making decisions	In all of our main decisions, think about the views of people with lived experience This is for decision making in the advisory groups, and for other decision in the Review
	Reporting	When we report findings and make recommendations, we connect these to the views and experiences of people with lived experience

Accountability	Getting evidence	Gather evidence in the context of our human rights framework and report on this
	Making decisions	Make decisions within a human rights framework, and based on evidence gathered within a human rights framework
	Reporting	Make recommendations within a human rights framework, and based on evidence gathered within a human rights framework

Non-discrimination and equality	Getting evidence	Give priority to people who may face the biggest barriers to having their rights met Assess our approach for getting evidence, to make sure that it promotes equality and human rights
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9.1 The review's human rights based approach

	Making decisions	When making decisions, priorities the human rights of people who face the biggest barriers to realising their rights Assess our approach for making decisions, to make sure that it promotes equality and human rights
	Reporting	Assess the potential impact of our recommendations, to check that they could promote equality and human rights

Empowerment	Getting evidence	All autistic people and people with learning disability with an interest in the review will be offered support to understand the relevant rights We will try to make sure that support is there for all people to take part
	Making decisions	Some autistic people and people with learning disability will advise the review on how to run the Review These people will be fully supported to understand the relevant rights, and be fully supported to take part in the advisory groups
	Reporting	Reports will be accessible for all people who may be interested in them

Legality	Getting evidence	We will ask legal experts to give us advice on how to get our evidence
	Making decisions	We will ask legal experts to give us advice on how to on how to understand our evidence when we are making decisions
	Reporting	We will ask legal experts to give us advice when we are making our recommendations, to make sure that we have understood the law

9.1 The review's human rights based approach

The FAIR process

We can use the FAIR process at each stage of the Review. For example for Stage 1: Get evidence on people's experiences of the 2003 Act

Facts	Make sure that people have the support that they need to take part in the review
	Get information on the operation of the 2003 Act: law, regulations, monitoring data, existing reviews and research, and so on
	Get new information on the experiences of people who have been subject to the Act, from: (1) people with learning disability or autism (2) carers (3) professionals who have used the Act
	Decide what the important facts are to understand (based on people's experiences)
Analysis	Identify the human rights issues
	Analyse what we find, in relation to different types of human rights (Absolute, qualified and limited human rights are explained in reference (1), which is given at the bottom of this page)
	Think about whether any restrictions on human rights are justified and proportional
Identification of shared responsibility	Identify what facts we need to know next
	Find out who can give us those facts
	Decide how we will get this evidence
Review actions	Analyse what people told us about how it was to take part in the Review in Stage 1. Use these findings to tell us what to do in the next stage of the review When analysing the evidence that we get in Stage 2: check that we have got the evidence that Stage 1 told us to get
	When we analyse the evidence that we get in Stage 2: check that we have got the evidence that Stage 1 told us to get

9.2 Materials: Human rights framework

Purpose: We used the framework to guide us in setting our question, to bring together evidence from all people, and to enable us to give equal weight to evidence from all people.

A human rights framework was needed as part of the human rights based approach to this review. The review follows the Scottish Human Rights Commission's human rights based approach, which is described at:

http://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

The human rights framework is the main tool that the review uses to comply with the Legality principle of the human rights based approach.

We aimed to have a framework that is broad enough to cover all aspects of the Mental Health Act (the 2003 Act) and to cover all areas of human rights that may be most relevant to mental health law. This framework is meant to:

- give us a foundation for reviewing any aspect of 2003 Act
- help us to see any gaps that may exist in the 2003 Act in the context of current human rights standards
- make it possible for us to put together all of the evidence that we get, which will come from a very wide range of sources.

To develop our framework, we started with the five themes set out in the World Health Organisation's QualityRights (WHO QR) indicator framework. Each theme in that framework corresponds to a right under the Convention on the Rights of Persons with Disabilities (CRPD), but themes in that framework can include more than one CRPD right.

We then expanded the WHO QR framework to include -

- relevant absolute rights: the right to life, in addition to the right to freedom from torture, inhuman and degrading treatment.
- relevant rights from the European Convention on Human Rights (ECHR): there was generally some overlap – and sometimes tension – between CRPD and ECHR rights, and the framework reflects this.
- the principles of the CRPD: These are found in Article 1. They are included because they are fundamental to the CRPD and because the 2003 Act is based on principles.
- other CRPD rights that are particularly relevant: for example, the 2003 Act sets up arrangements for monitoring the operation of that Act, and Article 33 of the CRPD deals with monitoring.

9.2 Materials: Human rights framework

The review's Secretary and Project Manager developed versions of this framework for comment. A lawyer with expertise in human rights based approaches and mental health law proposed plain English descriptions of the relevant content of each human right. The review's Independent Chair and members of the review's Law and Policy Advisory Group commented on this framework.

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9.2 Materials: Human rights framework

What should happen for you

Theme	The name of the theme	Easy read description of the theme	Full text description of the theme	Main CRPD rights in this theme
1	Standards of living	Standards of living	The right to an adequate standard of living and social protection	Articles 22 and 28
2	Health	Achieving your best level of health	The right to enjoyment of the highest attainable standard of physical and mental health	Article 25
3	Freedom and safety	Being able to make your own decisions, and being free and safe	The right to exercise legal capacity and the right to personal liberty and the security of person	Articles 12, 13, 14 and 17
4	Protected from abuse	Not being tortured or treated cruelly, and not being used or abused	Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse	Articles 10, 15 and 16
5	Independent living	Independent living and being a part of the community	The right to live independently and be included in the community	Articles 19 and 26

9.2 Materials: Human rights framework

How things should happen for you

Theme	The name of the theme	Easy read description of the theme	Full text description of the theme	Main CRPD rights in this theme
A	Dignity	Dignity	Disabled people have the same rights as everybody else	Article 1
B	Equality and non-discrimination	Being equal	Everyone is equal under the law and that discrimination against disabled people will not be allowed	Articles 5, 6 and 7
C	Accessibility	Accessibility	Disabled people have equal access to things in all areas of life	Article 9
D	Implementation and monitoring	Information and making rights happen	Countries collect the information they need to help make this agreement happen, and disabled people can access this information.	Articles 31 and 33

9.2 Materials: Human rights framework

Each theme in detail: **What** should happen for you

Theme 1: Standards of Living

Number		Article	Right	What is required	Examples
1	1	Article 22 CRPD / Article 8 ECHR	Respect for privacy	No unreasonable interference with your privacy, especially personal and health information	I can keep things private when I want to I have a private life
1	2	Article 28 CRPD	Adequate standard of living and social protection	Adequate living conditions, including in healthcare and residential facilities	I like the place where I live
1	3			Continuous improvement of their living conditions	The place where I live is getting better and better, not worse
1	4			An adequate standard of food, clothing, clean water	I like the food I eat I can have a drink when I need to
1	5			Devices and other assistance that people need for their disability	I can get help with my disability when I need it
1	6			A decent social environment with things to do and connections with the outside world	I have things to do I have people to see

9.2 Materials: Human rights framework

Theme 2: Health

Number		Article	Right	What is required	Examples
2	1	Article 25 CRPD	Right to health	Care and treatment for your mental health and physical health has to be: Available – there are enough people & places to provide healthcare and there is enough information	I can get help with my health when I need it
2	2			Care and treatment for your mental health and physical health has to be: Accessible – everyone should be able to get healthcare equally. It shouldn't be too expensive or too hard to get to and everyone should be able to understand the information	I get information about my health and how to get help I can understand this information Cost does not stop me from getting the care and treatment that I need
2	3			Care and treatment for your mental health and physical health has to be: Acceptable – to everyone, even if they have different cultures	My care and treatment is acceptable for my culture
2	4			Care and treatment for your mental health and physical health has to be: Quality – meeting good standards	I like the help I get for my health The help I get for my health is good

9.2 Materials: Human rights framework

2	6			You have the right to healthy conditions, including safe drinking water, safe and healthy food, decent housing, information and education about health	The place where I live helps me to be healthy.
2	7			People with disabilities have the right to the same standards of healthcare as anyone else.	The help I get for my health is as good as other people get.
2	8			If people need healthcare because they have a disability, or to prevent it becoming worse, they must be given it.	I get help to live with learning disability I get help to live with autism
2	9			People with disabilities, like anyone else, have the right to make choices about their healthcare.	I can make choices about my health I can make choices about the help I get for my health.
2	10			Staff must make sure they don't treat people differently because they have a disability.	I am treated the same way as everyone else

9.2 Materials: Human rights framework

Theme 3: Freedom and safety

Num ber		Article	Right	What is required	Examples
3	1	Article 12 CRPD	Equal recognitio n before the law	Systems based around supported decision-making	I have made an advance statement
3	2			When needed, to be given support to make decisions and exercise legal capacity	I am supported to make decisions I can get advocacy when I need it I can have a lawyer if I need one
3	3			Respect for the rights, will and preferences of disabled people	My advance statement was used to help make decisions about my care and treatment People listened to me at tribunals Health professionals respected my rights and what I want
3	4			A move away from substitute decision-making (decisions made by others)	I can make decisions about my life Other people do not make decisions for me about my life
3	5	Article 13 ECHR	Right to an effective remedy	Everyone whose rights and freedoms are violated will have an effective remedy	I wasn't happy about my care and treatment, but I got things changed

9.2 Materials: Human rights framework

3	6	Article 13 CRPD	Access to justice	That justice systems are accessible to disabled people so they can participate – as the person concerned, as witnesses. Information, communication, physical environment and financial costs must all be accessible. Accommodation to make procedures accessible	<p>I know how to challenge decisions about my care and treatment</p> <p>I can challenge decisions about my care and treatment</p> <p>I can take part in my tribunals in every way</p> <p>I can take part in my own trial in every way</p>
3	7	Article 13 CRPD	Access to justice	Training for people working in the justice system on these issues	People in the justice system have the skills that they need to make the justice system accessible for me
3	8	Article 6 ECHR	Right to a fair trial	Fair hearing and due process, including having the opportunity to participate effectively in hearings, having enough information and time to prepare for a hearing	<p>My tribunal was fair</p> <p>My trial was fair</p>

9.2 Materials: Human rights framework

3	9	Protocol 7, Article 2 ECHR	Right of appeal in criminal matters	Everyone convicted of a criminal offence by a tribunal shall have the right to have his conviction or sentence reviewed by a higher tribunal	I know that I can sometimes appeal the decision of a Mental Health Tribunal I know that I can sometimes appeal the decision of a court
3	10	Article 14 CRPD	Liberty and security of person	No detention based on disability (in tension with 3 12)	I know why I am here I am here for care and treatment I am here to stop me from hurting myself I am here to stop me from hurting someone else I am here because I have a learning disability I am here because I have autism
3	11			Informed consent to admission to healthcare / residential settings	I understand why I am here, and I am choosing to be here
3	12	Article 5 ECHR	Right to liberty and security	No unjustified detention (in tension with 3 10)	I know why I am here I am here for care and treatment

9.2 Materials: Human rights framework

					<p>I am here to stop me from hurting myself</p> <p>I am here to stop me from hurting someone else</p> <p>I am here because I have a learning disability</p> <p>I am here because I have autism</p>
3	13			<p>Procedures and safeguards when a person is detained e.g. information about why you have been detained, the opportunity to challenge your detention</p>	<p>I understand why I have been kept here</p> <p>I know what to do if I think I should not be kept here</p>
3	14	Article 17 CRPD	Protecting the integrity of the person	Free and informed consent to treatment	I can say no if I don't want treatment / medicine / to see a health worker
3	15	Article 8 ECHR	Right to respect for private and family life	Not to be interfered with without your consent, unless it is necessary.	<p>I can have visitors that I want to see</p> <p>I can see people in private that I want to see</p> <p>People can give me things that I want to have when I am here</p>

9.2 Materials: Human rights framework

Theme 4: Protection from abuse

Num ber		Article	Right	What is required	Examples
4	1	Article 10 CRPD / Article 2 ECHR	Right to life	Duty not to take away anyone's life	Being here stops me from hurting other people
4	2			Duty to take reasonable steps to protect life	Being here stops me from hurting myself
4	3			Remedies when things go wrong, including investigating	If something goes wrong I know who to speak to If something goes wrong I know people will help to make it better
4	4	Article 15 CRPD / Article 3 ECHR	Freedom from torture or cruel, inhuman or degrading punishment	Treatment which causes severe harm, or is grossly humiliating and undignified must never occur	My treatment doesn't hurt me. My treatment doesn't upset me. My treatment doesn't harm me.
4	5			Duty to take reasonable steps to protect from risks of ill-treatment	People always do everything that can be done to treat me with respect
4	6			Remedies when ill-treatment occurs, including investigating	I told someone that I was not being treated with respect, and now I am treated with respect

9.2 Materials: Human rights framework

4	7	Article 15 CRPD	Freedom from torture or cruel, inhuman or degrading punishment	No participation in medical or scientific experiments without free consent	<p>If the person has taken part in experiments:</p> <p>I had a choice in whether to take part in experiments</p> <p>I had support that I needed to help me decide whether to take part in experiments</p>
4	8	Article 16 CRPD	Freedom from exploitation, violence and abuse	Take steps to prevent abuse, including through information and support on how to deal with it	<p>I know what abuse is</p> <p>I know what to do if I think I am being abused</p>
4	9			Effective independent monitoring of facilities and programmes for disabled people	I have someone I can trust who will check that my care and treatment is right
4	10			Measures to help people recover if they have been victims of abuse	I was not treated with respect, but people helped me to recover

9.2 Materials: Human rights framework

Theme 5: Independent living

Num ber		Article	Right	What is required	Examples
5	1	Article 19 CRPD	Living independently and being included in the community	To decide where, with whom and how to live and individualised support to allow that to happen	I can live where I want I can live with people I want to live with I get support to live how I want to live
5	2			Not to be obliged to live in a particular arrangement e.g. in an institution in order to receive mental health services	I can live where I want to live I don't have to live in a hospital / care home / (place where the person doesn't want to live)
5	3			Full participation in all aspects of the community e.g. education, work, public life, leisure and sport.	I feel that I am part of my community
5	4			All services in the community for the general population must also be available, universally accessible, acceptable and adaptable to disabled people.	I can use all the services in my community

9.2 Materials: Human rights framework

5	5	Article 26 CRPD	Habilitation and rehabilitation	Take steps to allow disabled people to achieve and keep their independence and participation in all aspects of life.	I get support to be independent / I get support to be part of my community
5	6			Ensure there are services available for this as early as possible	I have support for things to get better in all of my life: for my health, for work, for learning and for living well

9.2 Materials: Human rights framework

Each theme in detail: **How** things should happen for you

Theme A: Dignity

Number		Article	Right	What is required	Examples
A	1	Article 1 CRPD	Purpose [of the UNCRPD]	Respecting a person's choices.	I can make choices in my life
A	2			Respecting that having a disability doesn't mean there is something "wrong" with a person – it just means they are different and should be accepted for who they are.	People accept me for who I am

9.2 Materials: Human rights framework

Theme B: Equality and non-discrimination

Number		Article	Right	What is required	Examples
B	1	Article 5 CRPD	Equality and non-discrimination	Take positive steps to remove barriers and ensure disabled people have equal opportunities	I have the same opportunities as everyone else
	2			Ensure accessibility	<p>I can use all of the services that I need</p> <p>I understand my care and treatment services</p> <p>I can get to my care and treatment services</p>
	3			Provide reasonable accommodation [reasonable adjustments] and individual supports when needed	My care and treatment fit my needs as a person with a disability
B	4	Article 14 ECHR	Equality and non-discrimination	Enjoyment of rights and freedoms without discrimination on any ground	I am treated the same as everyone else

9.2 Materials: Human rights framework

B	5	Article 6 CRPD	Women with disabilities	Positive steps need to be taken to ensure that women with disabilities are protected against things being worse for them because of being both a woman and having disabilities (multiple discrimination)	Being a woman does not mean I am treated differently
B	6	Article 7 CRPD	Children with disabilities	Particular attention to children with disabilities	People always make sure that I have what I need
B	7			The best interests of the child have to come first	People have made decisions for me that are the best decisions for me
B	8			Listen to children's views and respect them for who they are as they grow up.	Adults listen to me and treat me well
B	9			Give disabled children assistance to express their views if they need it	People help me to say what I think or want

9.2 Materials: Human rights framework

Theme C: Accessibility

Number		Article	Right	What is required	Examples
C	1	Article 9 CRPD	Accessibility	Systematic removal of barriers to access	<p>I can use all of the services that I need</p> <p>I understand my care and treatment services</p> <p>I can get to my care and treatment services</p>
	2			Universal design in all new facilities, services etc	<p>If the person has access to new services or facilities that are also used by other people:</p> <p>Everyone can use the services that I use</p> <p>Everyone can use the buildings that I use</p>

9.2 Materials: Human rights framework

Theme D: Implementation and monitoring

Number		Article	Right	What is required	Examples
D	1	Article 31 CRPD	Statistics and data collection	Collection of disaggregated data (broken down into groups) to inform implementation of rights	<p>I know that people use information about me to make sure that my rights are met</p> <p>I know that people use information about people with my condition to make sure that our rights are met</p>
D	2	Articles 4.3 and 33 CRPD	National implementation and monitoring	Involving disabled people, through their representative organisations, in all activities to do with CRPD – implementing legislation and policies, monitoring the convention.	I have been helped to make sure that people's human rights are promoted and protected

9.3 Materials: Outcomes framework

Purpose: We use this list to guide discussions with organisations in stage 2, when we asked for suggestions on how the law could be in future. It came from stage 1 evidence.

List of outcomes

This is a list of outcomes for Scotland's mental health law, for autistic people and people with learning disability

The next pages tell you more about the main outcomes.

	Why we are talking about 'outcomes for mental health law'	2
A	People are safe in a crisis	3
B	All decisions promote and protect the person's human rights	4
C	Medicine has a positive effect for the person	6
D	Care and treatment have positive effects for the person	7
E	Criminal justice is fair and helpful for the person	9
X	The law promotes and protects all of the person's human rights	10

These outcomes will promote and protect human rights.

9.3 Materials: Outcomes framework

Why we are talking about ‘outcomes for mental health law’

Scotland’s Mental Health Act should promote and protect the human rights of autistic people and people with learning disability.

This review is working to find out how well the Mental Health Act does this. The review might find that the law needs to change.

An outcome is a difference or an impact that is made to people.

Any change to the law should aim for more good outcomes and fewer bad outcomes for people.

Outcomes help us to look at where we should be, so that we can work out how to get there.

The review team has written a list of outcomes for Scotland’s mental health law.

We think that the law could help to achieve all of these outcomes.

These are outcomes that Scotland’s law needs to achieve to promote and protect people’s human rights.

Where the outcomes came from

Some outcomes are based what people told us about their experiences of the Mental Health Act.

Some outcomes are based on what people with lived experience or professionals have written about the Mental Health Act in Scotland, or about care, treatment or criminal justice in Scotland.

9.3 Materials: Outcomes framework

The law

In stage 2 of this review, we are asking people to think about what needs to be in the law to make these outcomes happen.

For some outcomes, the Mental Health Act may already be the best that the law can be.

For other outcomes, it may be that mental health law could be improved.

There may be some outcomes that cannot be achieved at this time.

The review is trying to think through all options, so that we can understand what outcomes can be achieved, and what the law can do to help to achieve those outcomes.

9.3 Materials: Outcomes framework

A: People are safe in a crisis

What needs to happen to achieve this outcome

A1	When people are at risk of suicide , other people recognise this and make sure the person has the support that they need.
A2	People's assessments for care, treatment and support are based on a real understanding of the person. The assessments help to prevent crisis .
A3	All people have their support co-ordinated effectively
A4	People have specialist care which is well-planned and prevents crisis.
A5	Professionals are accountable and serious incidents are investigated well.
A6	People have the support that they need when they are very stressed or very distressed
A7	People have effective support to get through a crisis , wherever they are living
A8	People feel safe where they are
A9	People can have someone they can talk to, in private, who they can trust

9.3 Materials: Outcomes framework

B: All decisions promote and protect the person's human rights

What needs to happen to achieve this outcome

B1	<p>People's rights, will and preferences are the basis for all decisions.</p> <p>Decisions are not based on other people's views about the person's best interests.</p> <p>Offenders will have some restrictions on this right. Offenders with disabilities will not have more restrictions than other offenders.</p>
B2	People have fair opportunities to challenge professionals
B3	When a person has to be physically restrained , this is done in a way that prevents trauma, injury or death.
B4	Each person has the least restrictive option available to them.
B5	People are under compulsion in the community for the shortest possible time
B6	People can choose to stay in their home area and can choose to return home from other areas if they want to
B7	People get out of hospital when they are well
B8	People are not restrained or put in seclusion unless this is needed to protect the right to life. If it is necessary it is always done in a way that promotes and protects the person's human rights.
B9	People can choose whether to have their carers involved in decisions about their care and treatment
B10	For people who cannot communicate their will and preferences, all decisions include knowledge and understanding of the person's will and preferences.
B11	People have all the support they need and want for making their own decisions

9.3 Materials: Outcomes framework

B12	People receive and understand all the information they want and need. This includes information about rights, care and treatment.
B13	When people are making decisions, or when decisions must be made for people, people have all of the input that they need from professionals
B14	When people have to be restricted in any way: The restrictions are fair and proportionate The restrictions are clearly explained . This includes explaining what has to change to reduce the restrictions. The restrictions are reviewed regularly The person is fully involved in reviewing the restrictions.

9.3 Materials: Outcomes framework

C: Medicine has a positive effect for the person

What needs to happen to achieve this outcome

C1	People are not prescribed psychotropic medication when it is not approved to be used in that way , unless it needed to protect the right to life
C2	People are not given psychotropic medication without their agreement , unless this is needed to protect the right to life
C3	People are always offered other care and treatment before psychotropic medication is given without the person's agreement
C4	People are not prescribed psychotropic medication when they have concerns about serious adverse effects from those medicines
C5	People's absolute rights are always respected when psychotropic medication is used
C6	All people who are taking psychotropic medication have regular medication reviews . They are supported to come off any medication that is not approved to be used in that way.

9.3 Materials: Outcomes framework

D: Care and treatment have positive effects for the person

What needs to happen to achieve this outcome

D1	All people feel understood and accepted by services
D2	All people can get the right care and treatment for them
D3	People have the support that they need from services when they express stress or distress
D4	People's mental health services are accessible to them in every way
D5	All people have access to good diagnosis and assessment
D6	All people have access to the rehabilitation, habilitation and employment support that they need
D7	All of the person's health, care and support needs are met, including physical health and support to stay healthy
D8	People's absolute rights are always respected in all care and treatment
D9	People have environments for their care and treatment that promote and protect all of their human rights. This includes quiet, private space for people to use when they choose to use it.
D10	People's private and family lives are promoted and protected. People are accepted by other people, and people can have visitors in hospital when they want to.

9.3 Materials: Outcomes framework

E: Criminal justice is fair and helpful for the person

What needs to happen to achieve this outcome

E1	People in the criminal justice system can be diagnosed and are supported throughout the criminal justice system
E2	All of the person's human rights are promoted and protected in rehabilitation in the community
E3	Disabled offenders are not restricted more than any other person who presents the same risk
E4	People in the criminal justice system have full access to mental health services which help to rehabilitate and which prevent harm to the person
E5	People can have trials , with the adjustments that the person needs for the trial
E6	People have legal representatives who support their needs well
E7	People can be given the full range of sentences , with adjustments made to meet people's needs
E8	People are not put in situations where they are likely to cause serious harm to other people

9.3 Materials: Outcomes framework

X: The law promotes and protects all of the person's human rights

What needs to happen to achieve this outcome

X1	The law promotes dignity and equality, and protects people from discrimination.
X2	The law makes sure that Disabled Persons Organisations exist. The law makes sure that Disabled Persons Organisations have influence and can help to create, implement and monitor the systems and services that protect their human rights.
X3	People's rights, will and preferences are the basis for all decisions. Decisions are not based on other people's views about the person's best interests. Offenders will have some restrictions on this right. Offenders with disabilities will not have more restrictions than other offenders.
X4	The law makes sure that people with disabilities who are in the criminal justice system have all of their human rights promoted and protected. Offenders with disabilities will have some restrictions on their rights. Disabled offenders are not restricted more than any other person who presents the same risk
X5	The law leads to the end of people being treated or detained without their agreement because they have a disability
X6	The law prevents all care, treatment and support that is cruel, inhuman or degrading.

9.3 Materials: Outcomes framework

X7	<p>The law makes sure that all services for persons with disabilities are accountable and are monitored independently and effectively.</p> <p>The law also makes sure that professionals meet their duties and act within their authority.</p>
X8	<p>The law ensures people's right to live independently and be included in the community.</p> <p>This right is restricted for offenders with disabilities. Disabled offenders are not restricted more than any other person who presents the same risk</p>
X9	Absolute rights are always protected by law.
X10	Mental health law works well with other laws to promote and protect human rights.
X11	Mental health law has a definition of 'disability' that works with our international human rights obligations .
X12	The law promotes and protects people's mental health
X13	The law makes sure that all professionals have all the skills that they need to support people well
X14	The law makes sure that reasonable adjustments are made for people
X15	When people with disabilities have to have their rights restricted because they present a risk to other people's right to life, those people with disabilities only experience the same negative effects from the law that anyone else would experience .
X16	Professionals relate to people as equals and use their authority in a fair way
X17	The law makes sure that children with disabilities have the mental health services they need in their community
X18	The law makes sure that people of all genders have access to appropriate mental health services and criminal justice services

10 Materials: Communication

These materials were used in the advisory groups or to enable people to take part in the review.

10.1 Governance: example of advisory group paper

Purpose: Papers enabled our discussions at advisory groups.

For the fourth advisory group meeting.

Paper 2: Stage 3 of the review

This paper is for Session 2 of the Advisory Group meeting

What is in this paper

This paper explains what has to happen in stage 3.

The paper says how stage 3 fits in to the rest of the review.

We will ask for your suggestions on how to do stage 3.

You are welcome to ask us any questions.

You can make any comments or suggestions that you want to make at the meeting, and for **up to two weeks** after the meeting.

A	Stage 3 and the other parts of the review	2
B	Times for stage 3	3
C	How stage 2 will affect stage 3	4
D	What the review has to do in stage 3	7
E	Your suggestions for stage 3	9

10.1 Governance: example of advisory group paper

A. Stage 3 and other parts of the review

Stage 1: September 2018 - February 2019

We heard about people's experiences
We collected stories about people's experience of the Mental Health Act



Stage 2: March 2019 - July 2019

We are working out what needs to change and what needs to stay the same in the Mental Health Act.
We are doing this with people with lived experience and professionals



Stage 3: August 2019 - November 2019

We will tell everyone what we have found out.
We have to ask everyone what they think about what should stay the same and what should change in the Mental Health Act.



Reporting: December 2019

The Executive will write and agree the report and recommendations.
The Chair will make these recommendations to the Minister for Mental Health

10.1 Governance: example of advisory group paper

B. Times for stage 3

The detailed times for stage 3 are shown in the shaded boxes in the table below. Our fifth meeting will now be in August.

Months	Stage	Tasks for the Review	Advisory group meetings
June to August 2018	Developing tools, testing approach		First meeting
September to November 2018	Stage 1	Consultation	Training (optional) Second meeting
December 2018 to January 19	Stage 1	Analysis and reporting	Third meeting
February 2019	Developing tools		
March to May 2019	Stage 2	Consultation	Fourth meeting
June to July 2019	Stage 2	Analysis and reporting	
July to August 2019	Developing tools		Fifth meeting in August, not June
August to November 2019	Stage 3	Consultation, analysis and reporting	
December 2019	Report to Minister		Sixth meeting

10.1 Governance: example of advisory group paper

C. How stage 2 will affect stage 3

Stage 2 was about what should happen **in the future**.

Stage 3 will be about what **people think about the options**. The 'options' will be the suggestions that the review team choose and give to people for consultation.

Stage 2 gave us evidence about how the law **could be better at promoting and protecting human rights**.

Stage 3 will give us evidence about how changes to the law **could make things better, or could make things worse**.

At the end of stage 3 we need to **understand what people think about the options for mental health law** for autistic people and people with learning disability from Scotland.

On the next pages, you can see how the review's remit fits in to stage 2 and stage 3.

10.1 Governance: example of advisory group paper

Stage 2 – how could things be better	Stage 3 – what changes to the law could make things better
<p>We are looking at how can people be better served by the Mental Health Act</p> <p>We are looking at how people’s human rights can be better promoted and protected by law</p> <p>We are thinking about what can be changed in mental health law to better promote human rights.</p>	<p>We may suggest some changes in the law</p> <p>People will say whether they think the changes would meet people’s needs or not.</p> <p>People will say whether they think that changes would better promote and protect people’s human rights or not.</p>
<p>We are looking at the issues that are most important to people</p> <p>We are looking at how these issues affect people’s human rights.</p>	<p>We may suggest some changes in the law.</p> <p>People with will say whether or not they think the changes we suggest are about the issues that are most important to them.</p>
<p>We are looking at how prescribing of medicine can better promote human rights</p>	<p>We may suggest some changes in the law.</p> <p>People will say whether or not they think these changes will promote human rights in prescribing of medication.</p>

10.1 Governance: example of advisory group paper

Stage 2 – how could things be better	Stage 3 – how changes to the law could make things better
<p>We are looking at how the role of psychology in the Mental Health Act could change to better promote human rights.</p>	<p>We may suggest some changes in the law.</p> <p>People with will say whether or not they think these changes will promote human rights in the use of psychology, and the role of psychologists.</p>
<p>We are looking at how the Mental Health Act and Criminal Justice System should interact, to better promote human rights.</p> <p>We are thinking about how the criminal justice system would be affected by any change in the law that we suggest.</p>	<p>We may suggest some changes in the law.</p> <p>People with will say whether they think these changes will better promote human rights for people involved in the criminal justice system.</p>
<p>We are looking at whether the definition of “mental disorder” should change in the Mental Health Act to better promote and protect human rights.</p>	<p>We may suggest some changes in the law.</p> <p>People with will say whether they think that any changes in to the definition of “mental disorder” will better promote and protect human rights.</p>

10.1 Governance: example of advisory group paper

D. What the review has to do in stage 3

The time and resources that we have for stage 3

We will have two months to consult in stage 3.

It will take until the end of August to set up the consultation for stage 3.

The consultation will be open from the last week of August until the last week of October

At the end of October, we will need to analyse what people have told us in stage 3.

In November, we need to think through what people have said to us in stage 3. We have to make sure that the things people tell us can have an effect on the report and recommendations.

We will need a lot of time to create the report. We must finish the report in December.

We have asked Scottish Government to pay for more support for the review in stage 3.

10.1 Governance: example of advisory group paper

Meetings that might be needed in stage 3

The executive might need to meet with some organisations or individuals in stage 3.

After the executive has decided what options to consult about, the executive will be able to decide what organisations or individuals to meet with. Those meetings might need to be in September.

For example, we might consult about an option that would have a big effect on how one professional group would work in future. We may need to meet with that group to really understand how the suggestion could affect them.

If we decide to consult about an option that is complex in the law, we might need to meet some experts in that area of law.

In the consultation, some organisations or individuals might tell us that they have big concerns about some of the options.

In November, after the consultation finishes, we may need to meet with some organisations or individuals to make sure that we understand their concerns.

10.1 Governance: example of advisory group paper

E. Your suggestions for stage 3

Catherine will talk about this before we begin.

The aim of stage 3 is to understand what people think about our options for mental health law.

We would like to talk with you about how we can help people and organisations to be ready to take part when stage 3 starts.

We would like to talk with you about how people can get the information and support they need to take part in stage 3.

Catherine will remind you about the sort of information and support that people had in stage 1 and stage 2.

There is a list of questions to think about on the next page.

In your smaller advisory groups we will ask you to share your ideas and discuss them together.

Please write down everyone's ideas and comments.

It's OK if you don't have any ideas. You can listen to other people and make comments and suggestions in your group. Or you can suggest things after the meeting by email or phone.

Things to consider:

The options in stage 3 will be complicated.

People will need time to understand the information.

We have two months to complete stage 3 consultation.

We will need to hear from people with lived experience and professionals.

Stage 3 will focus on the law, not on people's experiences.

We will ask people to tell us what they think about the suggestions for law.

10.1 Governance: example of advisory group paper

Questions sheet

Do you think that we have the right **aim for stage 3**?
Our aim is to understand what people think about our options.

Was there **anything that we did in stage 1 or stage 2** that could help people to take part in stage 3?

What do you think we should do in stage 3 that would be **new or different** from stage 1 and stage 2?

In stage 3 we will have to talk about some complex changes to the law. In stage 3, how could we include **people who do not use speech to communicate**?

10.1 Governance: example of advisory group paper

If you have made suggestions about things that we could do in stage 3, then you could answer these questions too:

My suggestion is: _____

What are the **good things** about your suggestion?

Is there **anything that might stop your suggestion** from working?

Do you know about any **examples of your suggestion** being done for another project that we can learn from?

10.2 Stage 1: Talking Mats

Purpose: To enable people with limited verbal communication to tell the review about their experiences of the Mental Health Act, in stage 1 of the review.



Here is an example of some of the pictures in the review's Talking Mats symbol set.

The review worked with the Talking Mats organisation, who developed sets of symbols that the review's executive could use to communicate better with people who use limited speech. Talking Mats is described [here](#). It uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them. In this review, the space was a physical, textured mat. Topics are whatever the interviewer wants to talk about. Options relate specifically to each topic. For example: 'What do you feel about....?' The Top Scale allows participants to indicate their general feelings about each topic and option. The meaning of the visual top scale can be adapted to suit the questions to the person, for example, whether they are happy, unsure, or unhappy.

In this review, the symbols were organised into three sets (topics). Two members of the review's executive were trained in Talking Mats and worked with people with learning disability in hospitals in Scotland. People could choose to talk about one, two or three topics, or none. Once the topic was chosen, the participant was given the options one at a time and asked to think about what they feel about each one. They then placed

10.2 Stage 1: Talking Mats

the symbol under the appropriate visual scale symbol to indicate what they feel. The review team noted the responses, including any comments that the person made on each symbol.

The range of symbols was designed to make it possible for people to talk about the whole range of rights in the review's human rights framework. However, the symbols did not map directly onto human rights concepts. Talking Mats works with concrete concepts (real things). Human rights tend to be about more abstract ideas.

10.3 Stage 1: Easier survey

Purpose: To enable people to communicate their experiences of the Mental Health Act easily, using the standard range of topics in stage 1.

Easier survey for people with learning disability or autistic people

Welcome to this survey

This is a survey about your experiences of the **Mental Health Act**.

These questions are for you if you are autistic or if you have learning disability.

You should **only** answer these questions if you have been on an order under the Mental Health Act.

This means you have been given medicine or treatment for your mental health without you saying it is OK.

Or it means you have been made to stay in hospital when you didn't want to.

How to do the survey

It is up to you if you do this survey or not.

You can miss out questions if you don't want to answer them.

You can stop the survey and come back to it later if you want.

Someone can help you with this survey.

You can ask someone you trust to help you.

Someone you know might be able to help you with the survey.

Or you can email the review team at irmha.scot@nhs.net

Or you can phone the review team at 0131 313 8744.

10.3 Stage 1: Easier survey

How the review will look after your information

We will keep the information you give us private.

We will not share your survey with anyone else.

We will not tell anyone that you did the survey.

If any of your answers make us think that you or someone else is in serious danger, then we will share this information with someone who can help.

Contact us if you want to know more about we will do with your information.

You can email the review team at irmha.scot@nhs.net

Or you can phone the review team at 0131 313 8744.

You need to send your answers to us by 30th November 2018.

10.3 Stage 1: Easier survey

A: About you

1. Your name

You do not have to answer this.

Title like Mr or Ms: _____

First name: _____

Middle name(s): _____

Last name: _____

2. Do you have learning disability?

- Yes
- No
- Don't know

3. Do you have autism?

- Yes
- No
- Don't know

4. Where do you live?

- In hospital
- At home
- Somewhere else

10.3 Stage 1: Easier survey

5. Are you under the Mental Health Act now?

- Yes
- No
- Don't know

6. Why were you put under the Mental Health Act?

- Because of mental illness
- Because of behaviour
- Because of a crime
- I don't know
- For another reason – please write the reason in here

10.3 Stage 1: Easier survey

B: Your experience of the Mental Health Act

This section is all about your experiences. You can tell us as much or as little as you want to.

1. When you were put under the Mental Health Act, what was it like?	<input type="checkbox"/> It was OK <input type="checkbox"/> I am not sure <input type="checkbox"/> It was not OK
Tell us anything you want to about what happened when you were put under the Mental Health Act	
2. What is being under the Mental Health Act like for you?	<input type="checkbox"/> It is OK <input type="checkbox"/> I am not sure <input type="checkbox"/> It is not OK
What help have you had that made things better for you?	
What happened that made things worse?	

10.3 Stage 1: Easier survey

<p>3. What was it like when you stopped being under the Mental Health Act?</p>	<p><input type="checkbox"/> It was OK <input type="checkbox"/> I am not sure <input type="checkbox"/> It was not OK <input type="checkbox"/> I have never stopped being under the Act</p>
<p>Tell us anything you want about what happened when you stopped being under the Mental Health Act</p>	
<p>Criminal justice system The criminal justice system is the police, the courts and prison.</p>	
<p>4. Were you in the criminal justice system when you were put under the Mental Health Act?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I do not know</p>
<p>5. What was being in the criminal justice system like?</p>	<p><input type="checkbox"/> It was OK <input type="checkbox"/> I am not sure <input type="checkbox"/> It was not OK</p>
<p>What was good and bad about the criminal justice system?</p>	

10.3 Stage 1: Easier survey

C: Your human rights

The next part is about your **human rights**.

We are asking about the time when you were on an order under the Mental Health Act. This might be now or in the past.

You can tell us about some of these things or all of these things



1. My health and care



2. The place where I live



3. Having a say and making choices



4. How people treat me

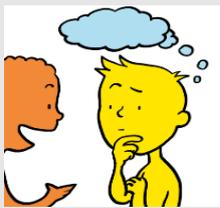
10.3 Stage 1: Easier survey

1. My health and care

Do you want to tell us about your health and care under the Mental Health Act?

Yes

No

	<p>1. Have you been given medicine under the Mental Health Act?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't know</p>
	<p>2. What do you think about being given medicine?</p>	<p><input type="checkbox"/> It was OK</p> <p><input type="checkbox"/> I am not sure</p> <p><input type="checkbox"/> It was not OK</p>
	<p>3. Were you given information about your medicines and treatment?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> No</p>
	<p>4. Did you understand the information about your medicines and treatment?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> No</p>
<p>Tell us what is good and bad about your medicine and treatment under the Mental Health Act:</p>		

10.3 Stage 1: Easier survey

	<p>5. Do you have choices about your medicine or treatment?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
---	---	--

	<p>6. Have you written down your choices about the care and treatment you want?</p> <p>This can be called an advanced statement.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
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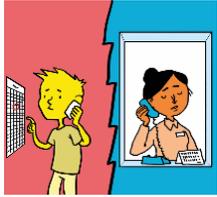
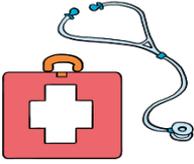
Tell us anything you want to about having choices about your health care, under the Mental Health Act:

	<p>7. Have you had help from staff to change how you think, feel and behave?</p> <p>This is called psychological help</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
---	--	--

	<p>8. What did you think of the psychological help that you got?</p>	<input type="checkbox"/> OK <input type="checkbox"/> Not sure <input type="checkbox"/> Not OK
--	--	---

Tell us about the help you got to change how you think, feel and behave, under the Mental Health Act:

10.3 Stage 1: Easier survey

	9. Can you get help for your health when you need it when you are under the Mental Health Act?	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
	10. What do you think about the help you get for your physical health under the Mental Health Act?	<input type="checkbox"/> OK <input type="checkbox"/> Not sure <input type="checkbox"/> Not OK
Tell us anything else about the help you got for your health when you are under the Mental Health Act:		

10.3 Stage 1: Easier survey

2. The place where I live

Do you want to tell us about the place where you live when you are under the Mental Health Act?

Yes

No

	<p>1. What do you think about the place where you live when you are under the Mental Health Act?</p>	<p><input type="checkbox"/> OK</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> Not OK</p>
	<p>2. What do you think about the activities you have to do?</p>	<p><input type="checkbox"/> OK</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> Not OK</p>
	<p>3. What do you think about the food and drink that you get?</p>	<p><input type="checkbox"/> OK</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> Not OK</p>
	<p>4. Can you see visitors when you want to see them?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> No</p>

Tell us anything else you want to about activities, food and drink or visitors when you are under the Mental Health Act:

10.3 Stage 1: Easier survey

	<p>5. When you are under the Mental Health Act, do you feel safe in the place where you live?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
	<p>6. If you live in hospital under the Mental Health Act do the staff help you to feel safe?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
<p>Tell us anything you want to about feeling safe when you are under the Mental Health Act:</p>		
	<p>7. Do you have a private place where you live when you are under the Mental Health Act?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
	<p>8. Do you live where you want to live when you are under the Mental Health Act?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
	<p>9. Do you feel part of a community?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
<p>Tell us anything else you want to about where you live when you are under the Mental Health Act:</p>		

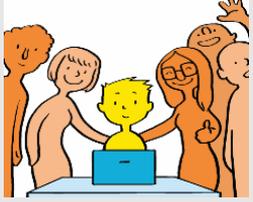
10.3 Stage 1: Easier survey

3. Having a say and making choices

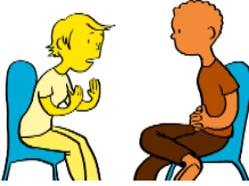
Do you want to tell us about having a say and making choices when you are under the Mental Health Act?

Yes

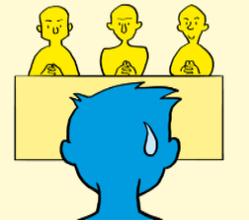
No

	<p>1. Do people listen to you when you are under the Mental Health Act?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> No</p>
	<p>2. Do you make decisions about your life, when you are under the Mental Health Act?</p>	<p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Never</p>
	<p>3. What do you think about other people making decisions about your life?</p>	<p><input type="checkbox"/> It's OK</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> Not OK</p> <p><input type="checkbox"/> This doesn't happen</p>
	<p>4. Do you make decisions about your medicine and treatment when you are under the Mental Health Act?</p>	<p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Never</p>
<p>Tell us anything you want to about being listened to and making decisions under the Mental Health Act:</p>		

10.3 Stage 1: Easier survey

	<p>5. Do you have support from an independent advocacy worker when you are under the Mental Health Act?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
	<p>6. What did you think about the advocacy worker?</p>	<input type="checkbox"/> OK <input type="checkbox"/> Not sure <input type="checkbox"/> Not OK

Tell us anything you want to about support from advocacy:

	<p>7. Have you ever been to a tribunal?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
	<p>8. Did people listen to you at your tribunal?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No

Tell us anything you want to about going to a tribunal:

10.3 Stage 1: Easier survey

4. How people treat me

Do you want to tell us about how people treat you?

Yes

No

	<p>1. How do staff treat you when you are under the Mental Health Act?</p>	<p><input type="checkbox"/> OK <input type="checkbox"/> Not sure <input type="checkbox"/> Not OK</p>
	<p>2. Do staff treat you the same as other people?</p>	<p><input type="checkbox"/> Always <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p>
	<p>3. Do staff and other people accept you for who you are?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No</p>
	<p>4. Do you get support from staff to do things yourself?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No</p>
<p>Tell us anything you want to about how staff treat you when you are under the Mental Health Act</p>		

10.3 Stage 1: Easier survey

	5. How do other people treat you, like the people on your ward or community?	<input type="checkbox"/> OK <input type="checkbox"/> Not sure <input type="checkbox"/> Not OK
	6. Do you have someone you trust who you can talk to?	<input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/> No
Tell us anything you want to about how people treat you when you are under the Mental Health Act:		

10.3 Stage 1: Easier survey

D: More questions about you

This is the last section.

1. Where you live

What is your home town or village? This is the place where you usually live, even if this is not where you are living just now.

2. Hospital

Are you living in a hospital now?

- Yes
- No

If you are in hospital, how long have you been in hospital?

- Less than one week
- Between one week and one month
- More than one month
- More than one year
- I don't know

3. Where you had care and treatment

Where did you last have care and treatment under the Mental Health Act?

- At home
- Away from home, but not far from my home
- Far away from home, but in Scotland
- Outside of Scotland

4. How old are you?

10.3 Stage 1: Easier survey

5. When were you last under the Mental Health Act?

- Now
- Within the last year
- More than a year ago
- More than five years ago
- I don't know

Thank you

This is the last page of the survey. Thank you for your answers.

If you give us your email address, we will email you. We will tell you more about the review. We will tell you about other any other chances to help with the review.

You can give your email address here if you want to:

You can say anything else that you want to say here:

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10.4 Stage 2: Examples

Purpose: To guide discussion with organisations in stage 2 of the review. In stage 2, organisations made suggestions on how the law could better promote and protect human rights in future. Organisations chose to discuss these examples with the review, team or the list of outcomes in 9.3. These examples were based on what we heard in stage 1.

Examples for stage 2

These examples are not real, they are made up.

They are not stories about real people.

They reflect some of the different people and different situations that the law needs to work for.

The examples are to help us to think about what will need to happen for different people in different situations, to protect and promote their human rights.

10.4 Stage 2: Examples

Example 1

A person with learning disability commits an offence. The usual prison sentence for their offence would be 10 years.

Instead of having a trial, the person is diverted to hospital where they are placed on an order which means they can be kept in hospital for as long as they need to be in hospital.

The person is moved around, sometimes to places far away from their family. They have been in hospital for 15 years.

In hospital the person has been able to have therapies that have helped them. They are very glad not to be in prison. They feel they would not commit the same offence again.

The person does not like the other people who live in the hospital ward. Sometimes the person gets worried or angry and hits out. When this happens, the person is restrained by nurses. Sometimes they are put in seclusion.

The person waits for months for meetings to take place. At the meetings, it often feels that nothing is going to change.

Sometimes meetings are cancelled and decisions are made without the person knowing what is happening.

The person does not know when they will be allowed to leave hospital. They don't know what they have to do to prove that they won't commit another offence.

The person is scared sometimes. If they feel staff have been unfair to them they do not tell anyone because they are worried they will be punished. They cannot speak to anyone in private because all their phone calls and visits are supervised.

Questions for Example 1

1. How can the law make sure that this person supported to feel safe where they are?
2. How can the law make sure that this person is involved in the decisions that affect their human rights?
3. How can the law protect the person's right to private life and family life?
4. How can the law make sure that the person is not restricted more than any other person who presents the same risk?
5. How can the law make sure that restraint and seclusion are only done if this is absolutely necessary, and in a way that promotes and protects the person's human rights?
6. What else can the law do to make sure the criminal justice system is fair and helpful for this person?
7. What else can the law do to make sure this person's human rights and other people's human rights are protected and promoted?

10.4 Stage 2: Examples

Example 2

A person is in hospital. The person has learning disability and autism, and does not communicate with speech.

The person came into hospital because they have learning disability and there was a risk that they might hurt other people. The person might also have a mental illness but that is not the main reason why they are made to stay in hospital under the Mental Health Act.

Some of the things that the person did caused problems for other people. One day they got upset and hit out at their support worker and ran away from home. So the person was taken to hospital under the Mental Health Act.

In hospital the person can be kept safe and looked after by trained nurses and other staff. They can get support for any health issues they have and support to communicate.

In hospital the person was given medicine. The medicine was given to them to make them calm, not to treat mental illness. The person's family members did not want them to be given this medicine but they could not stop it from happening. They say the medicine has made the person like a zombie.

The person has been in hospital for 8 years. The hospital they live in is 100 miles away from their home.

The person has now been told they are fit to leave the hospital. This means that they are well and they could live in the community. However there is no other safe place for them to live in, so they have to stay in hospital.

While the person has been in hospital they have stopped doing a lot of the things they used to enjoy doing. They have put on weight.

Questions for Example 2

1. What should the law do to make sure that this person has the help that they need when they are in crisis?
2. How can the law make sure that this person is involved in the decisions that affect their human rights?
3. How can the law make sure that decisions about the person are based on the person's will and preferences (based on what the person wants)?
4. How could the law make sure that care and treatment have positive effects for this person?
5. How could the law make sure that medicine has a positive effect for the person?
6. How could the law help to make sure that person can get out of hospital when they are well?
7. What else can the law do to make sure this person's human rights and other people's human rights are protected and promoted?

Example 3

A woman thinks she might be autistic but she has not had a diagnosis. She has tried to get help from mental health services but they said there was nothing they could do to help her, because she does not have a mental health problem.

The woman has been feeling more and more like she cannot cope. She tried to tell people about this but they didn't seem to listen.

The woman was admitted to hospital because she said she wanted to kill herself. In the hospital there was no privacy. She was watched all the time by staff who sat close to her, in her room. This felt painful to her.

The woman was not allowed to hide under her bed covers. She was not allowed to shower on her own.

The woman could not eat the food that was offered to her because she does not eat gluten. She told the staff this but nothing was done. When the woman refused to eat the food she was punished by being made to sit in her room.

The woman was not allowed any of the things that help her to stay calm. These things were taken away because she would not behave in the way that people were asking her to behave.

After a while a staff member who had good awareness of autism suggested that the woman might have autism. The woman got a diagnosis, and then got some of the care and treatment that she needed. This made things better.

Questions for Example 3

1. What should the law do to make sure that this person has the help that they need when they are in crisis?
2. How can the law make sure that this person is involved in the decisions that affect their human rights?
3. How could the law make sure that care and treatment have positive effects for this person?
4. How can the law make sure that when this person is in hospital, the environment promotes and protects their human rights?
5. How can the law make sure that the person has equal access to care and treatment, as a woman?
6. How can the law make sure that mental health services are accessible to this person in every way?
7. What else can the law do to make sure this person's human rights and other people's human rights are protected and promoted?

10.5 Stage 3: Easy read consultation – one part

Purpose: To enable people to comment on the proposals that the review's executive made in stage 3 of the review.

Autism and learning disability as disabilities

10.5 Stage 3: Easy read consultation – one part



At the moment autism and learning disability are called mental disorders in law.

We think this needs to change.

We think the law should say that autistic people have autistic impairments.

Also, the law should say that autistic people are disabled sometimes.

We think the law should not say 'learning disability'. It should talk about people with intellectual impairments.

Also, the law should say that people with intellectual impairments are disabled sometimes.

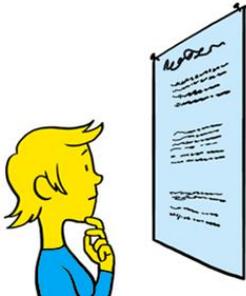
10.5 Stage 3: Easy read consultation – one part

Sam's story



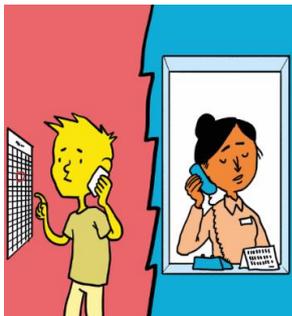
Sam has learning disability and autism.
A lot has changed in Sam's life.
She has been feeling upset and worried.
She has started running away from home.

What could happen now



At the moment the law says Sam has mental disorder.

This means she can be made to go to a mental health hospital. This can happen if she is doing something that is risky.



Sam's family are worried about her.

They call the doctor.

The doctor thinks that Sam should go to hospital to get some new medicine.

Sam does not want to go to hospital.

Sam's parents agree to take her to hospital because they think it would help.

When she is there Sam feels worse. She is scared. She does not know anyone there.



10.5 Stage 3: Easy read consultation – one part

What could happen in future



In the future we think the law should not say that Sam has a mental disorder.

Instead the law should say that Sam sometimes has a disability.

A disability does not last forever.

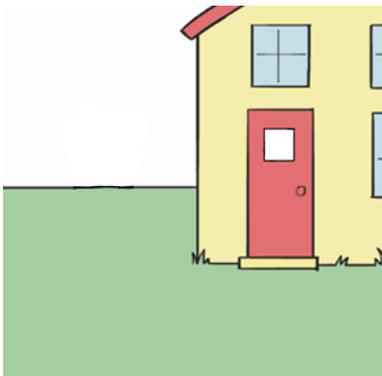
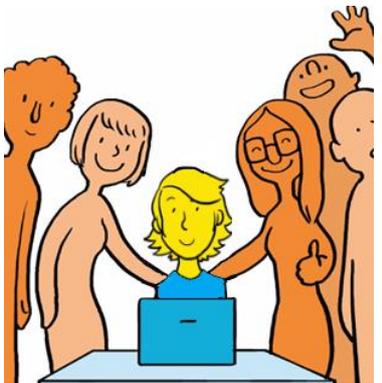
It is caused by a mixture of the things in Sam's life, and Sam's learning disability and autism.

For example when changes happen around Sam, it makes Sam upset.

A new law says that Sam must get all the support she needs to feel better when she is very upset.

Local services have to give Sam all the support she needs in her home.

Sam is not taken to hospital because people know this would not help her disability.



Questions

One main idea is that learning disability and autism are not called mental disorders in the law.

Instead, the new law would say that autistic people and people with intellectual impairments can sometimes be disabled.

1. What do you think about the ideas in this section?

- I like the ideas
- I have mixed views about the ideas
- I do not like the ideas
- I do not understand the ideas

2. Why do you think that?

3. Could these ideas be made better?

- Yes
- No
- I don't know

4. How could these ideas be made better?

10.5 Stage 3: Easy read consultation – one part

Another main idea is that there should be a new law to make sure that people can have the right support, care and treatment to help with disability.

A new law should make sure that people are never made to stay in a hospital environment that would make their disability worse.

1. What do you think about the ideas in this section?

- I like the ideas
- I have mixed views about the ideas
- I do not like the ideas
- I do not understand the ideas

2. Why do you think that?

3. Could these ideas be made better?

- Yes
- No
- I don't know

4. How could these ideas be made better?

11 Who took part in the review

The executive

Andrew Rome was the independent chair of the review. He is a mental health nurse who has been involved in the design, development and evaluation of drug and alcohol policy, procedures and services for over 25 years. Andrew was a member of the Scottish Social Services Council. He is a clinical tutor in drug misuse and alcohol brief interventions for the Royal College of General Practitioners in Scotland. Andrew is a judicial member of the Mental Health Tribunal for Scotland.

Andrew was publicly appointed by the Scottish Government as the review's independent chair and was self-employed.

Other members of the review's executive were employed by the Mental Welfare Commission for Scotland for the review.

Andrew directed their work, not the Mental Welfare Commission.

Simon Webster was the secretary to the review. Simon was in charge of carrying out the review. He has worked with and for autistic people and people with learning disability for over 20 years. His work has been in independent advocacy, social work, social care and research.

Simon had a fixed-term contract for his work with the review.

Catherine Evans was the project manager for the review. Catherine is a Public Involvement Co-ordinator at Midlothian Health and Social Care Partnership, with NHS Lothian.

Catherine was seconded from NHS Lothian for her work with the review.

11 Who took part in the review

Advisors

Advisory group members advised the executive on how to run the review so that the review got the evidence it needed.

The review's executive did not ask these advisors for advice on what to say in the review's reports or recommendations.

The advisors were not responsible for the review, its reports or its recommendations. Advisors did not have to agree with what the review team did.

We thank the advisors for their work. A few advisors with lived experience remained anonymous for some or all of the review, for personal reasons. The review's executive allowed this to make it possible for all advisors to participate.

Law and Policy Advisory Group

Expertise	Advisor
Autism	Leo Starrs-Cunningham
Experiences of people who do not communicate with speech	Audrey Edwards
Learning disability	Kerry McInnes
Human rights-based approaches	Cathy Asante
Scottish Mental Health Law	Jane Patrick
International human rights law	Jill Stavert

11 Who took part in the review

Care and Treatment Advisory Group

Expertise	Advisor
Autism	Catriona Stewart
Experiences of people who do not communicate with speech	Gemma Graham
Learning disability	Person with lived experience
Psychiatry	Laura Cameron
Psychology	Keith Bowden
Social work	Gillian MacIntyre

Criminal Justice and Mental Health Advisory Group

Expertise	Advisor
Autism	John Grafton
Autism	Person with lived experience
Learning disability	James McNab
Nursing	Lynn Gill
Prison	Rosemary Duffy
Psychiatry	Jana De Villiers

11 Who took part in the review

Communication and engagement advisory group

Expertise	Advisor
Autism	Cal M
Intellectual disability	John Feehan
Experiences of people who do not communicate with speech	Thom Kirkwood
Advocacy	Carina Mitchell
Engagement	Catriona Rowley
Engagement	Ali Jones (first meetings)

We also had single meetings with other groups of people who could advise us on how to engage with children, and on how to engage with carers.

Ad hoc advisors

We asked ad hoc advisors for advice on how to run the review when we needed advice from other sources:

Kabie Brook, engagement with autistic people

Professor Sally-Ann Cooper, monitoring of public health

Professor Jean Maclellan, engagement with the autism community

Dr Gary Morrison and then Colin Mckay, monitoring of mental health law

Susan Gowland, engagement with people with learning disability in stage 1

11 Who took part in the review

Legal experts

The review's executive asked for perspectives from some legal experts near the end of the review process, to help them to test the ideas for law reform that they developed from the review's evidence. The experts volunteered their time. They did not give legal advice or opinion and are not responsible for this report or its recommendations. The review's executive thanks these experts, who were:

Cathy Asante

David Cobb

Ronald Franks

Andrew Lennon

Alex Ruck Keene

Leo Starrs-Cunningham

Professor Jill Stavert

11 Who took part in the review

We thank all individuals and organisations for taking part. In this section we list the organisations and experts that took part in the review. We do not list the names of individual people with lived experience, to protect their privacy. Another report from this review, an evidence resource, gives information on how many people and organisations took part in the review.

Stage 1: Experience of the Mental Health Act

In stage 1, we met individuals who had lived experience of the Mental Health Act. We invited professionals and organisation to complete a survey on their experiences

Lived experience organisations:

Autism Rights

People First Scotland

Scottish Women's Autism Network

Professional organisations:

Autism Treatment Plus

British Psychological Society

Enable Scotland

Forensic Network

NHS Grampian Learning Disability Services

Heads of Learning Disability Service Scotland (Clinical Psychology)

Law Society of Scotland

Mental Health Tribunal for Scotland

11 Who took part in the review

Midlothian Health and Social Care Partnership

Midlothian Mental Health Social Work Team

Mental Welfare Commission for Scotland

Royal College of Occupational Therapists

Royal College of Psychiatrists

Shetland Community Health and Care Partnership

Scottish Independent Advocacy Alliance

Scottish Learning Disability Senior Nurse Leads Group

11 Who took part in the review

Stage 2: Suggestions for the law in future

In stage 2, we invited lived experience organisations and professional organisations to meet with us. This was to give us suggestions on how the law could better promote and protect human rights in future.

Lived experience organisations:

Advocating Together, Dundee

Autistic Mutual Aid Society of Edinburgh

Association for Real Change / National Improvement Network

Autism Rights

Autism Rights Group Highland

Edinburgh and Lothian Aspergers Society

ENABLE ACE groups

Inclusion Scotland

Keys to Life expert group

Learning Disability Alliance Scotland

National Autistic Taskforce

PASDA (Parents of ASD Adults), Edinburgh and Lothians

People First Scotland

Scottish Women's Autism Network

Our Voice, SENSE, Dundee and Glasgow

Support in Mind – relatives of forensic patients

Supporting Offenders with Learning Disability

Triple As, Aberdeen

Professional organisations:

11 Who took part in the review

Autism Initiatives

Autism Network Scotland

British Psychological Society

Children and Young People's Commissioner for Scotland

Convention of Scottish Local Authorities

Downs Syndrome Scotland

ENABLE Scotland

Equality and Human Rights Commission

Forensic Network

Heads of Learning Disability Services Scotland (Clinical Psychology)

Independent Inquiry into Mental Health Services in Tayside

Law Society of Scotland

Mental Health Tribunal for Scotland

Mental Welfare Commission for Scotland

National Autistic Society Scotland

Police Scotland

Royal College of Occupational Therapists

Royal College of Psychiatrists

Royal College of Speech and Language Therapists

Scottish Association of Social Workers

Scottish Commission for Learning Disability

Scottish Human Rights Commission

Scottish Independent Advocacy Alliance

Scottish Learning Disability Nurse Network

Scottish Learning Disability Observatory

Social Work Scotland

11 Who took part in the review

Stage 2: Experts

The review team spoke with experts whose knowledge helped them to develop ideas on how the law should be in future. Experts with lived experience were invited to contribute, but none accepted the invitation.

The fact that an expert took part in the review does not imply that they agree with the recommendations. The experts are not responsible for the recommendations.

Paula	Arnold	Divisional Head, Women's Strategy Programme, Scottish Prison Service
Michael	Bach	Managing Director, IRIS – Institute for Research and Development on Inclusion and Society / Adjunct Professor, Disability Studies, Ryerson University, Toronto, Canada
Dr Gill	Bell	Northgate Hospital, Morpeth, Northumberland, England
Prof. Jerome	Bickenbach	Disability Policy Unit, Swiss Paraplegic Research, Nottwil, Switzerland
Dr David	Branford	Lead Pharmacist, STOMP, NHS England and NHS Improvement, England
Colin	Caughey	Director (Legal, Research and Investigations, and Advice to Government), Northern Ireland Human Rights Commission, Northern Ireland

11 Who took part in the review

Prof. Sally-Ann	Cooper	Institute of Health and Wellbeing, University of Glasgow, Scotland
Dr Gavin	Davidson	Professor of Social Care, Education and Social Work, Queens University, Belfast, Northern Ireland
Dr Mhairi	Duff	Lead Clinician, Intellectual Disability Services, Mason Clinic Regional Forensic Psychiatry Services, Auckland, New Zealand
May	Dunsmuir	President of the Health and Education Chamber of the First-tier Tribunal for Scotland
John	Farrelly	Chief Executive, Mental Health Commission, Republic of Ireland
Prof. Kirsty	Forsyth	National Autism Integration Team, Scottish Government and Queen Margaret University, Scotland
Prof. Kris	Gledhill	Professor, AUT Law School, Auckland, New Zealand
Dr Piers	Gooding	Research Fellow, Melbourne Social Equity Institute and Melbourne Law School, University of Melbourne, Australia
Dr Claire	Henderson	PhD FRPsych, Reader in Public Mental Health, King's College London Institute of Psychiatry, Psychology and Neuroscience and Honorary Consultant Psychiatrist, South London and

11 Who took part in the review

		Maudsley NHS Foundation Trust, England
Dr Veronica	Holland	Head of Victims and Witnesses of Crime Branch & Violence Against the Person Branch, Department of Justice, Northern Ireland
Nicola	Howard	Course Lead, Approved Mental Health Professional course, Swansea University, Wales
Joyce	Johnston	Service Manager, The Moray Council, Elgin, Scotland
Tom	Kelly	General Manager, Specialist Learning Disability Services, NHS Greater Glasgow & Clyde, Scotland
Mat	Kinton	National Mental Health Act Policy Advisor, Care Quality Commission, England
Margaret	Lougher	Course Lead, Approved Mental Health Professional course, Swansea University, Wales
Boyd	McAdam	National Convenor, Children's Hearings Scotland. Now retired.
Dr Anne	McDonald	Institute of Health and Wellbeing, University of Glasgow
Duncan	McIntyre	Joint Planning and Implementation Officer, Midlothian Health and Social Care Partnership, Scotland

11 Who took part in the review

Jackie	Mcrae	Practice and Partnerships Lead, Children's Hearings Scotland
Mark	McSherry	Risk Management Authority, Paisley, Scotland
Prof. Bernadette	McSherry	Professor, Melbourne Social Equity Institute, University of Melbourne, Australia
Alex	Ruck Keene	Barrister and Visiting Lecturer, King's College London, England
Dr Amanda	Smith	Clinical Chief Advisor, Disability Directorate, Ministry of Health, New Zealand
Sinclair	Soutar	Executive Director, Kibble Secure Care, Paisley, Scotland
Anne	Webster	Clinical Lead, Learning Disability, STOMP, NHS England and NHS Improvement, England
Prof. Penelope	Weller	Graduate School of Business and Law, RMIT University, Melbourne, Australia
Lynn	Welsh	Head of Legal, Equality and Human Rights Commission, Scotland

11 Who took part in the review

Stage 2: Collaborative groups

Some people were invited to take part in a single collaborative group meeting. The groups were about –

- How decisions are made about care and treatment
- How decisions are monitored and governed
- How criminal justice can be fair and helpful for the person
- Legal experts

Most people with lived experience who took part were also advisors to the review. One person contributed in hospital.

Some professionals with relevant experience also took part in a group:

Sam Cairns, independent advocacy

Kim Seabrooke, communication and criminal justice

Colin McKay, mental health law and human rights

Wendy Sinclair Grieben, criminal justice and human rights

Bill Stevenson, equality and human rights

The collaborative group of legal experts involved the same advisors listed on page 121, except for Alex Ruck Keene.

11 Who took part in the review

Stage 3: Final consultation

In stage 3, the review's executive made proposals for how the law could be in future. Individuals and organisations gave their response to those proposals.

Stage 3: Organisations met in stage 3

The executive met with organisations that represent groups of people who could have been most affected by the stage 3 proposals.

Lived experience:

Autism Rights

Autism Rights Group Highland

Autistic Mutual Aid Society of Edinburgh

ENABLE ACE groups national meeting

National Autistic Taskforce

People First Scotland

Scottish Women's Autism Network

Supporting Offenders with Learning Disability

Health and social care management and governance:

Aberdeen Health & Social Care Partnership

Aberdeenshire Health & Social Care Partnership

Borders Health & Social Care Partnership

Chief Officers of Health and Social Care Partnerships

Chief Social Work Officers

Convention of Scottish Local Authorities

11 Who took part in the review

NHS Education for Scotland

North Highland Health and Social Care Partnership

Orkney Health and Care

Scottish Social Services Council

Specialist Learning Disability Services, NHS Greater Glasgow & Clyde

Professionals:

British Psychological Society

Forensic Network

Heads of Learning Disability Services Scotland (Clinical Psychology)

Health and Social Care Alliance Scotland (The Alliance)

Law Society of Scotland

Royal College of Psychiatrists

Scottish Association of Social Workers

Scottish Independent Advocacy Alliance

Scottish Learning Disability Nurse Network

Social Work Scotland

Stage 3: Organisations that responded in stage 3

Stage 3 included a survey that people and organisations could use to respond to the proposals. The review team made all responses from individuals anonymous. Most organisations gave permission for their names to be posted with their response.

11 Who took part in the review

Lived experience:

Advocating Together Dundee

Altogether4Change from Advocating Together, Dundee

Autism Rights

Autistic Mutual Aid Society Edinburgh

Edinburgh & Lothian Asperger Society

Edinburgh and Lothian Involvement Network

Inclusion Scotland

Inform Theatre

Mental Health Rights Scotland

National Autistic Taskforce

National Carer Organisations of Scotland

National Involvement Network

People First Scotland

Psychiatric Rights Scotland

Scottish Women's Autism Network

Supporting Offenders with Learning Disabilities

Values into Action Scotland

Professional:

British Medical Association

British Psychological Society

Convention of Scottish Local Authorities

Down's Syndrome Scotland

Dumfries and Galloway Council Social Work Services

East Ayrshire Health & Social Care Partnership

11 Who took part in the review

Forensic Network

Heads of Learning Disability Psychology Services Scotland

Key and Community Lifestyles Scotland

Law Society of Scotland

Midlothian Health and Social Care Partnership

NHS Education for Scotland

Royal College of Nursing Scotland

Royal College of Occupational Therapists

Royal College of Psychiatrists in Scotland

Scottish Association of Social Work

Scottish Human Rights Commission

Scottish Independent Advocacy Alliance

Scottish Social Services Council

Social Work Scotland

Specialist Learning Disability Service, NHS Greater Glasgow & Clyde

The Mental Welfare Commission for Scotland

The National Autistic Society Scotland

The Royal College of Speech and Language Therapists

The Scottish Commission for Learning Disability

12 A list of words in this report

Ad hoc	When needed
Autistic person	For some people, a description of how they are different from other people. For some people, a person who has a particular form of disability.
Autistic people's organisation	An organisation run by and for autistic people.
Convention	An agreement in law between countries.
Convention on the Rights of Persons with Disabilities	An agreement between countries that are members of the United Nations. It says what the rights of people with disabilities are. It says what governments
Council of Europe	An organisation for governments. These governments have agreed to the European Convention on human rights.
Disability	What a person experiences when they have impairments, and when there are barriers in society which affect them.
European Convention on Human Rights	An agreement between countries that are members of the Council of Europe.
Evidence	In this review, information that tells us something about how well the law promotes and protects human rights
Human rights	The basic rights and freedoms that belong to every person in the world.
Law	The rules a government makes for the people who belong to a country.

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Learning disability	Also called intellectual disability. A lifelong condition that affects how people understand information, learn skills and live independently.
Lived experience	Personal experience of autism, intellectual disability (learning disability), mental illness, or experience of caring for someone.
Mental disorder	The words used in the Mental Health Act to mean mental illness, learning disability or personality disorder, or similar conditions.
Mental health	The way you think, feel and behave.
Mental Health Act	The Mental Health (Care and Treatment) (Scotland) Act 2003. This is Scotland's main law about detention and compulsory care and treatment for mental illness, personality
Mental illness	A serious problem with mental health. The most common mental illnesses are depression and anxiety.
Mental Welfare Commission for Scotland	The organisation that looks after those who need help because of a mental disorder. They make sure that all treatment follows the law. People can speak to them at any time if they are unhappy about care and treatment.
Organisation of persons with disabilities	An organisation run by and for people with disability. The United Nations Committee on the Rights of Persons with Disabilities defines these in its general comment 7. You can click here to read this.

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Remit	A list of things that have to be thought about and reported on.
Scoping study	Work that is done before a review or project begins. This work helps to decide what the review or project will do.
Scottish Government	The politicians who are chosen to make decisions for Scotland, and the civil servants who support them in their work. The decisions include health, social care, justice, education,
United Nations	An international organisation. Its members are the governments of the world's countries. It works to keep international peace and security, to support countries to develop, and to promote and protect human rights.
Unpaid carer	A person who cares for another person without being paid. This is usually someone related to the person, but it can be a friend or someone else.

13 Response to organisations of persons with disabilities

The United Nations Convention on the Rights of Persons with Disabilities (the CRPD) required the review's executive to work with organisations of persons with disabilities. Thank you for working with us during the review process.

Guidance from the United Nations says this:

“Public authorities leading decision-making processes have a duty to inform organisations of persons with disabilities of the outcomes of such processes, including an explicit explanation in an understandable format of the findings, considerations and reasoning of decisions on how their views were considered and why.” ([link](#), paragraph 23).

This is our response to organisations of persons with disabilities that took part in this review. The response reflects our interpretation of this guidance.

We think that the guidance does not require us to give an individual response to each organisation that took part in the review. It would be very difficult to do this because the review and its recommendations are so complex.

We have written a general response to all organisations that explains what the outcomes of the review were, how their views were considered, and why they were considered in this way.

In future, other work may interpret the requirements to respond differently and, for example, may give a response to each organisation individually.

We are responding about:

1. The outcomes of the review process, including an explicit explanation in an understandable format of the findings
2. How your organisation's views were considered in the review process
3. Why your organisation's views were considered that way

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1. **Outcomes** of the review processes

The main outcome of the review is the final report. This is available in plain English. It is also available in easy read.

These reports have been sent out in print to organisations that asked for them.

The reports are available on the review's website at www.irmha.scot until June 2020.

The website will be archived by the National Records of Scotland and should become available by searching [here](#):

<https://www.nrscotland.gov.uk/research/researching-online/the-nrs-web-continuity-service/how-can-i-search-the-nrs-web-archive>

2. **How** the views of organisations of persons with disabilities were considered

The views of these organisations were considered by the review's executive, who made all decisions in this review.

Views of these organisations were given the same weight as the views of other organisations, including organisations of professionals. We used a human rights framework to bring together evidence and to give equal weight to evidence from all people.

Organisations of persons with disabilities expressed views in each stage of the review. The review's executive considered views after the end of each stage.

The review's executive used the views from these organisations in each stage of the review.

In stage 1, the executive used views to understand how people's human rights were affected by the Mental Health Act.

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The review's stage 1 report included views from these organisations. Some of the views were given through a survey. Some of the views were from reports that had been written by these organisations.

In stage 2, the executive used views to develop ideas on how the law could promote human rights better in future.

In stage 3, the executive used views to turn these ideas into proposals for how the law could better promote and protect human rights in future.

The views of organisations of persons with disabilities did influence the review's executive at each stage of the review, as did the views of other organisations.

Some examples of this can be seen by comparing the final consultation documents (stage 3), submissions from organisations of persons with disabilities, and the final report. This shows that the executive changed its proposals after the stage 3 consultation and that many changes reflected the views of organisations of persons with disabilities.

For example, in stage 3, the review's executive made proposals that rights should be limited for autistic people and people with learning disability as part of a separate law for these groups of people in future. The executive also proposed secure support centres in the community for people in crisis, and separate rehabilitation centres in the community for offenders, just for these groups of people. The review's executive proposed to define the terms autistic impairment, autistic disability, intellectual impairment and intellectual disability.

Some organisations of persons with disabilities disagreed with each of these proposals. The review's executive reconsidered

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each of these proposals. In the final report, each of these proposals was changed in important ways or was replaced.

The review's executive did not seek views from these organisations on how the review should be run. The review's advisory groups helped the review's executive to decide how to run the review. All advisors were expected to advise as individuals, not as representatives of organisations.

3. **Why** the views of organisations of persons with disabilities were considered in this way:

In general, the views of these organisations were considered in this way to involve organisations as much as possible in the review, while keeping the review independent. If organisations had made decisions on how their evidence should be considered, it would not have been an independent review.

In practice, the views of organisations were considered in this way after advice from the review's advisory groups. The membership of those groups was balanced between individuals with lived experience and individuals with professional experience. You can read about how those groups worked in a report called 'How we did this review'. This is available on the review's website until June 2020, when the website will be archived and taken down.

The review team also took this approach to enable all organisations of people with disability, and autistic people's organisations, to take part in ways that suited each organisation. Different organisations chose to take part in the review in different ways, to meet the needs and preferences of their members.



The independent review of
**Learning Disability
and Autism**
in the Mental Health Act